Living well for longer with metastatic breast cancer

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Chair, ABC Global Alliance and ABC Guidelines
ESMO Board of Directors & Director of Membership
ESO Breast Cancer Program Coordinator
DISCLOSURES SLIDE

Financial disclosures:
*Personal financial interest in form of consultancy role for:* Amgen, Astellas/Medivation, AstraZeneca, Celgene, Daiichi-Sankyo, Eisai, GE Oncology, Genentech, GlaxoSmithKline, Macrogenics, Medscape, Merck-Sharp, Merus BV, Mylan, Mundipharma, Novartis, Pfizer, Pierre-Fabre, prIME Oncology, Roche, Sanofi, Seattle Genetics, Teva.

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Non-Financial disclosures:
Chair ABC Global Alliance and ABC Consensus Conference and Guidelines. Member/Committee Member of ESMO, ESO, EORTC-BCG, IBCSG, SOLTI, ASCO, AACR, EACR, SIS, ASPIC.
Stage 1
Lymph node negative
(50-60% of BC diagnosed today)

Stage 2
Lymph node positive

Stage 3

Stage 4
INCURABLE!

Early stage

Advanced stage

Adjuvant systemic therapy

Chemotherapy +/-
Endocrine therapy +/-
Targeted therapy

Reach to Recovery International Conference 2019
DEFINITION OF ABC

Includes 2 clinical situations:

1. **Inoperable Locally Advanced Breast Cancer (LABC)**, that has not yet spread to distant sites

2. **Metastatic Breast Cancer**, that has spread to distant sites (most common are bone, liver, lung, brain, lymph nodes); also called Stage IV breast cancer.
Goals of the Treatment in ABC

- Balancing treatment efficacy and toxicity is the main objective
- Goals of treatment:
  - Improve survival *(very few agents achieve it!)*
  - Delay disease progression
  - Prolong duration of response
  - Palliate symptoms
  - Improve or maintain quality of life
  - Transform into a chronic disease
In the early 2000’s...
2 SURVEYS ON LIVING WITH ABC STARTED TO CHANGE THE SCENE...

• Most women do not feel that healthcare professionals, researchers, the media, women with EBC, and the governments pay enough attention to MBC.

• Throughout the survey there is a worrying picture of feelings of guilt, abandonment, isolation, and loneliness during the hard journey through MBC.

• 44% of respondents reported being afraid to talk open about their disease and 52% said their friends and family were uneasy talking about the disease.

Seminars in Oncology Nursing (26) 3, 2010; Community Oncology, Sep. 2010
TIME TO CHANGE!
ESO-MBC International Task Force

1300 attendees from 88 countries
1300 participants from 88 countries

www.abc-lisbon.org

https://oncologypro.esmo.org/Guidelines/
Several online presentations: e-ESO sessions, Peer Voice Program, Advocates Online Sessions, Breast Cancer TV, ...
WHY ARE GUIDELINES IMPORTANT?

• Unfortunately not all medical decisions can be based on level 1 evidence. Guidance is necessary.

• There is a wealth of (new) data in oncology that needs to be “digested”, put into perspective and applied to clinical practice.

• Patients in routine clinical practice are often very different from a clinical trial population.

• Many cancer patients are still treated totally outside the recommendations and available data!

• If all cancer patients would be treated according to the current knowledge, survival would substantially increase!
Resource-stratified guidelines: BHGI
Incremental allocation & implementation

- **Basic level**: Core resources or fundamental services necessary for any breast health care system to function.
- **Limited level**: Second-tier resources or services that produce major improvements in outcome such as survival.
- **Enhanced level**: Third-tier resources or services that are optional but important, because they increase the number and quality of therapeutic options and patient choice.
- **Maximal level**: Highest-level resources or services used in some high resource countries with lower priority on the basis of extreme cost.

If the costs associated with trastuzumab were substantially lower, trastuzumab would be used as a limited-level therapy.

<table>
<thead>
<tr>
<th>Level of resources</th>
<th>Locally advanced breast cancer</th>
<th>Systemic treatment (adjuvant or neoadjuvant)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Treatment Resource Allocation:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Locally Advanced Breast Cancer</td>
<td></td>
</tr>
</tbody>
</table>

Eniu A et al, Cancer: 113 (8 suppl), 2008

Courtesy Alex Eniu
Here & Now is a pan-European ABC awareness initiative from Novartis Oncology. The campaign aims to improve understanding of the high degree of unmet need, including the social and psychological impact of ABC, ultimately to improve support and care for patients across Europe.

Cardoso et al. Evolving psychosocial, emotional, functional, and support needs of women with advanced breast cancer: Results from the Count Us, Know Us, Join Us and Here & Now surveys. The Breast 28: 5-12, 2016.

5-year Survival Rates by Stage at Diagnosis (Female Breast Cancer, US SEER), 1992-1999 Compared with 2005-2011\textsuperscript{1,2}

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Localized (ie, cancer confined to the breast)</td>
<td>97.0</td>
<td>98.6</td>
</tr>
<tr>
<td>Regional (ie, cancer spread to regional lymph nodes)</td>
<td>78.7</td>
<td>84.9</td>
</tr>
<tr>
<td>Distant (ie, cancer has metastasized)</td>
<td>23.3</td>
<td>25.9</td>
</tr>
</tbody>
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Analysis suggests limited improvement in quality of life for patients with mBC over the last decade

Yes ... but not as much as needed!

Quality of life in patients with mBC as assessed by EQ-5D, 2004-2012, Generic (non-Cancer Specific) Health Utility Score\textsuperscript{2}

- An analysis of the trends in quality of life for mBC\textsuperscript{*} indicates that there has not been significant improvement over the past decade\textsuperscript{2}
- In fact, there has been a slight decrease in quality of life\textsuperscript{2}

\textsuperscript{*}Analysis was based on a review of 132 articles, of which a quantitative analysis was conducted of 14 studies reporting QoL measure values for mBC. Values are weighted based on sample size. This analysis indicates a numerical decrease over time. It does not intend to demonstrate statistical significance

CAN WE DO BETTER?

HOW?
The ABC Global Alliance
Continuing the work of the
ABC Consensus Conference
and Guidelines

The power of lobbying!

The ABC Global Alliance members

Members represented through Europa Donna - The European Breast Cancer Coalition (full list of countries available at www.europadonna.org)

mBA Alliance represents all its members in the ABC Global Alliance (full list of members available at www.mbaliaance.org)
ABC Global Alliance

Who We Are:

• A multi-stakeholder platform for all those interested in collaborating in common projects relating to advanced breast cancer (ABC) around the world.
• Continuation of the work developed through the ABC International Consensus Conference and Guidelines
• Launched during the World Cancer Congress in Paris on 3 November 2016

Our Vision/Mission:

• To improve and extend the lives of women and men living with ABC in all countries worldwide and to fight for a cure
• To raise awareness of advanced breast cancer and lobby worldwide for the improvement of the lives of ABC patients

Website www.abcglobalalliance.org
Email ABCGlobalAlliance@eso.net
Social media @ABCGlobalAll
ABC Global Charter
10 goals for the next 10 years

COMPREHENSIVE NEEDS ASSESSMENT DEFINES MOST URGENT AND ACTIONABLE GOALS
Done with (almost) all different stakeholders involved in ABC

1. HELP PATIENTS WITH ABC LIVE LONGER BY DOUBLING ABC MEDIAN OVERALL SURVIVAL BY 2025

2. ENHANCE OUR UNDERSTANDING ABOUT ABC BY INCREASING THE COLLECTION OF HIGH QUALITY DATA

3. IMPROVE THE QUALITY OF LIFE (QOL) OF PATIENTS WITH ABC

4. ENSURE THAT ALL PATIENTS WITH ABC RECEIVE THE BEST POSSIBLE TREATMENT AND CARE BY INCREASING AVAILABILITY OF ACCESS TO CARE FROM A MULTIDISCIPLINARY TEAM

5. IMPROVE COMMUNICATION BETWEEN HEALTHCARE PROFESSIONALS (HCP) AND PATIENTS WITH ABC THROUGH THE PROVISION OF COMMUNICATION SKILLS TRAINING FOR HCPs

6. MEET THE INFORMATIONAL NEEDS OF PATIENTS WITH ABC BY USING EASY TO UNDERSTAND, ACCURATE AND UP-TO-DATE INFORMATION MATERIALS AND RESOURCES

7. ENSURE THAT PATIENTS WITH ABC ARE MADE AWARE OF AND ARE REFERRED TO NON-ClinICAL SUPPORT SERVICES

8. COUNTERACT THE STIGMA AND ISOLATION ASSOCIATED WITH LIVING WITH ABC BY INCREASING PUBLIC UNDERSTANDING OF THE CONDITION

9. ENSURE THAT PATIENTS WITH ABC HAVE ACCESS TO TREATMENT REGARDLESS OF THEIR ABILITY TO PAY

10. HELP PATIENTS WITH ABC CONTINUE TO WORK BY IMPLEMENTING LEGISLATION THAT PROTECTS THEIR RIGHTS TO WORK AND ENSURE FLEXIBLE AND ACCOMMODATING WORKPLACE ENVIRONMENTS
**The Challenges of Extreme Societal Opinions about mBC**

<table>
<thead>
<tr>
<th>Death sentence</th>
<th>mBC Attitudes</th>
<th>Curable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some believe people with mBC will die very soon</td>
<td>Others overly positive, thinking people can “beat” mBC</td>
<td></td>
</tr>
<tr>
<td>Driven by perception that all cancer is terrible / imminently fatal</td>
<td>Typically driven by visibility of success stories in eBC</td>
<td></td>
</tr>
</tbody>
</table>
| Or by perception that once cancer spreads, end of life must be close | Patients themselves may believe their mBC can be cured  
  – in some cases, the medical team appears to have painted an overly positive picture |                                                                 |

48–76% of the general public believe that advanced/metastatic breast cancer is curable

**FIGHT STIGMA!**
Public perceptions may perpetuate the stigma and isolation for mBC patients

On average, 28% of the general population indicated that patients with mBC should keep it a secret and not discuss it with anyone other than their physician.

Percentage of respondents that felt people with advanced or metastatic breast cancer should not talk about it with anyone other than their physician

(% Agree somewhat/strongly - top 2 box)

14 Country Study: 14,315 respondents

mBC General Population Survey, commissioned by Pfizer. August 2015
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 that some patients can live with MBC 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.

(LoE/GoR: Expert opinion/A) (97%)
From the time of diagnosis of ABC, patients should be offered appropriate psychosocial care, supportive care, and symptom-related interventions as a routine part of their care. The approach must be personalized to meet the needs of the individual patient.

(LoE: Expert opinion/A) (100%)
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.

When possible, patients should be encouraged to be accompanied by persons who can support them and share treatment decisions (e.g. family members, caregivers, support network).

(LoE/GoR: Expert opinion/A) (100%)
Patients with mBC need realistic, compassionate and individualized communication.

Of 582 surveyed oncologists and other healthcare practitioners in the U.S., Europe, Latin America and Australia...

Less than 50% of healthcare professionals report having received training on how to bring bad news to patients and families.

There is a need for patients to proactively seek involvement in decision making.

Healthcare professionals reported that only half their patients voice their treatment goals.

Earlier discussion on end-of-life is needed to prepare patients.

In 65% of cases, end-of-life discussions are held too late - first arising after multiple changes in treatment have already occurred.

www.breastcancervision.com
www.abc-lisbon.org
EPIDEMIOLOGY OF ABC

CAN WE MANAGE PROPERLY WHAT WE CAN’T MEASURE?

• What is the prevalence of ABC?
  (most cancer registries capture diagnosis and mortality but not relapse!)

• What is the best endpoint for advanced cancer?
Incidence

HOW MANY ABC PATIENTS EXIST?

If 1 third would be MBC: about 2.2 million MBC patients
BUT it is just a very rough estimation

GLOBOCAN 2018 data*

5-year Prevalence

Evolution of OS over time

Evolution of OS over time

Observed Overall Survival From Diagnosis of Metastatic Disease

All Patients

National cohort of 19,898 MBC pts diagnosed between 01/2008 and 12/2016 and treated in 18 Comprehensive Cancer centers

Median FU for the whole cohort is 4.05 yrs [95 CI: 3.98-4.12]

<table>
<thead>
<tr>
<th>Period</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median OS</td>
<td>3.12</td>
<td>2.94</td>
<td>3.09</td>
<td>3.23</td>
<td>3.09</td>
<td>3.29</td>
</tr>
<tr>
<td>(95% CI)(yrs)</td>
<td>[2.92-3.31]</td>
<td>[2.78-3.09]</td>
<td>[2.94-3.24]</td>
<td>[3.02-3.48]</td>
<td>[2.89-3.25]</td>
<td>[3.09-ND]</td>
</tr>
</tbody>
</table>
Overall survival according to subtype

Prognosis of de novo & recurrent MBC diverges over time

*de novo* MBC
mean survival = 5.03 yrs.

Recurrent MBC
mean survival = 2.81 yrs.
Overall survival and sequential treatment of patients with MBC

- 134 sites, 298 oncologists, all over Germany
- > 3,700 pts/1409 ABC pts
- (goal: 4,500 BC pts/2250 ABC pts by end 2015)

Luminal is the most frequent subtype in ABC as well.

If a drug/class of drugs improves OS, it will change substantially the median OS of ABC

In press, The Breast 2017

Oral Presentation, ABC 2
Marschner, N, et al, TMK Registry Group
IMPROVING SURVIVAL

• STOP ACCEPTING PFS BENEFIT ALONE AS THE MAIN GOAL
• OS MUST BE AT LEAST A CO-PRIMARY
• INVEST IN LESS BUT “BIGGER” (SUFFICIENTLY POWERED) TRIALS
• COLLECT POST-PROGRESSION DATA
• USE REAL WORLD AND BIG DATA
Does PFS Benefit Matter If Not Associated With OS Benefit?

Depends!

• on the type of disease:
  • PD not always linked to symptoms (ovarian ≠ breast)
  • Available therapies

• on the type of drug:
  • Toxicity / QoL
  • Affordability
Strong consideration should be given to the use of validated PROMs (patient-reported outcome measures) for patients to record the symptoms of disease and side effects of treatment experienced as a regular part of clinical care.

These PROMs should be simple and user-friendly to facilitate their use in clinical practice, and thought needs to be given to the easiest collection platform e.g. tablets or smartphones.

Systematic monitoring would facilitate communication between patients and their treatment teams by better characterizing the toxicities of all anticancer therapies. This would permit early intervention of supportive care services enhancing QoL.

(LoE/GoR: I/C) (87%)
IMPROVING QUALITY OF LIFE

• STOP PRESCRIBING SO MUCH UNECESSARY CT
• NOT ALL PATIENTS NEED COMBINATION OF ET + TARGETED
• ADEQUATE SYMPTOM CONTROL (Opioids access)

• DEVELOP BETTER AND SPECIFIC QoL TOOLS
• ASK EXPERTS FOR HELP WHEN CHOOSING QoL TOOLS AND ENDPOINTS
Ongoing project:
Development of a QoL tool specific for ABC

Ongoing project:
Development of Quality Indicators for ABC/MBC
ESMO EUROPEAN AND GLOBAL OPIOID POLICY INITIATIVES

First-of-its-kind perception survey that provided recommendations to overcome barriers to access to opioids, including those on the WHO Essential Medicines List.

ESMO survey supported 2014 WHO Resolution on Palliative Care and the 2016 UN Outcome Statement on Controlled Substances.

The ESMO Designated Centres Programmes - 13 criteria for accreditation are based on WHO guidelines for palliative care, currently 200 accredited centres from around the world.

- Negative languages in Laws
- Restricted Dispensing Sites
- Burden of Prescriptions
- Pharmacist Authority
- Limited Prescription Duration <29 days
- Emergency Prescriptions
- Prescriber Restriction
- Eligibility Restriction

Bar chart showing the distribution of opioid policy initiatives across Middle East (gray), India (green), and Asia (brown).
NEED FOR CHANGE IN REIMBURSEMENT RULES
In many countries, current rules do not facilitate oral, less toxic treatments, nor shorter treatments of radiotherapy
Does being a patient have to be a full-time job?

Most doctors believe in holistic care, yet the clinical guidelines they use, and the way they discuss and deliver care, rarely take into account the demands that a given treatment option will make on the patient and their daily life. Additional reporting by Peter McIntyre.
As survival is improving in many patients with ABC, consideration of survivorship issues should be part of the routine care of these patients.

Health professionals should therefore be ready to change and adapt treatment strategies to disease status, treatment adverse effects and QoL, patients’ priorities and life plans. Attention to chronic needs for home and family care, job and social requirements, should be incorporated in the treatment planning and periodically updated.

(LoE/GoR: Expert opinion/A) (95%)
FINANCIAL IMPACT OF CANCER

• For the individual patient and family

• For society

HOW TO BALANCE THIS CONFLICT?

Human Life is Priceless

“...a few months can make a big difference – it means I could see my daughter graduate or see my grandchild.”

Doris Fenech, Opening lecture ABC2

All Resources Are Finite

NICE QALY Threshold

ICER of £20,000-30,000 per QALY gained
(above, therapy not cost-effective)

http://www.nice.org.uk/newsroom/features/measuringeffectivenessandcosteffectivenesstheqaly.jsp

ICER: incremental cost effectiveness ratio
Estimated total annual economic cost of cancer was US$ 1.16 trillion in 2010, about 2% of global GDP*

Reproduced with permission from the American Cancer Society.

R. Sullivan et al.
Delivering affordable cancer care in high-income countries.
Lancet Oncology, 2011, 12: 933-980

THE INDIRECT BURDEN OF CANCER

• Psychological burden (patient and family)
• Social burden
• Family burden (children, spouse...)
• Absence from work (productivity for society)
• Early retirement
• Premature death
Breast Cancer in Portugal in 2014:

- 1,646 deaths
- 13,425 years of life lost (YLL) due to premature death (98% due to ABC)
- 9,667 years lost due to disability (YLD)
- 23,092 DALYs (Disability Adjusted Life Years) - measure of burden of disease

- Total cost: 309 million euros = 0.18% Portugal PIB ≈ annual budget of a large hospital

(Courtesy Prof M. Borges)
At the individual level by stage

Stage I/II
Total = $82,121
- Surgery: 20%
- Drugs: 18%
- Other inpatient: 21%
- Other outpatient: 20%

Stage III
Total = $129,387
- Surgery: 16%
- Drugs: 20%
- Other inpatient: 16%
- Other outpatient: 29%

Stage IV
Total = $134,682
- Surgery: 15%
- Drugs: 25%
- Other inpatient: 9%
- Other outpatient: 28%
- Services: 5%

(Courtesy Prof R. Sullivan)
IMPROVING COST-EFFECTIVENESS

• TACKLE INDIRECT COSTS OF CANCER
• INVEST WISELY
• STOP WASTING RESOURCES
• USE GENERICS AND BIOSIMILARS
• USE AVAILABLE TOOLS TO PRIORITIZE
Approximately **half** of the women in employment had to change their work situation due to ABC⁹

37% of them have to give up work temporarily and or gave up work altogether⁹

56% of patients experienced a decline in household income as a result of ABC⁹
INDIRECT COSTS OF CANCER:
Loss in productivity of cancer survivors and advanced cancer patients

Economist Intelligence Unite survey. August-September 2016

CHANGE WORK-RELATED LAWS
Ability to work part-time, flexible timetables, work from home, fight stigma and prejudice at work...
Programme

14:00 Introduction
MEP D. Casa, European Parliament EPP, BE/MT
MEP L. Wierinck, European Parliament ALDE, BE

14:10 Difference between early and advanced breast cancer. The ABC Global Alliance and ABC Global Charter
F. Cardoso, Champalimaud Clinical Centre, Lisbon, PT and ABC Global Alliance Chair

14:20 Cancer Survivors, Long-Term side effects and Work
B. Wilson, Working with Cancer, Thames Ditton, UK

14:30 Employment/return to work issues facing patients with ABC
K. Benn, Europa Donna - The European Breast Cancer Coalition, Milan, IT

14:40 The financial impact of (advanced) breast cancer: direct and indirect (loss of productivity)
R. Sullivan, King's Comprehensive Cancer Centre, London, UK

15:00 Cancer in the Workplace. Available reports:
ABC Global Alliance
F. Cardoso, Champalimaud Clinical Centre, Lisbon, PT and ABC Global Alliance Chair
The Economist Intelligence Unit
T. Rosvall-Puplett (BMS)
The MBC Policy Roadmap
M. Hartka Kemppinen, Lilly International
My Time, Our Time Novartis Campaign
D. Decise (Novartis)
The road to a better normal
V. Clay (Pfizer)

15:20 How can the EU politicians/policy makers help?
MEP D. Casa, European Parliament EPP, BE/MT
MEP L. Wierinck, European Parliament ALDE, BE

15:30-15:45 Discussion and next steps
All participants

I have cancer but I want to work. Working rights of cancer patients.
An initiative of the ABC Global Alliance
7 November 2018, European Parliament, Brussels, BE

Report available soon on the Alliance website
Guidelines for managing patients with advanced breast cancer

General recommendations
- As management of ABC is complex it is crucial that it is carried out by a multidisciplinary team
- From diagnosis, patients should be offered routine psychosocial and symptom-related care
- The virtually incurable nature of the disease must be explained and discussed, as well as realistic treatment goals
- Patients and their families/caregivers (where appropriate) should be invited to take part in decision making
- As there are few proven standards of care, inclusion in clinical trials must be a priority whenever available
- Balanced decisions about costly treatment should be made, but patient preference, wellbeing and length of life should be the main decision factors
- Validated patient reported outcomes provide useful information and should be integrated with clinical assessments

Assessment
- Minimal staging work-up recommendations; tumour markers can be an aid; a framework for response to therapy; safe biopsies of metastatic lesions at first diagnosis; reassessment of ER and HER2 status at least once
- The panel did not recommend routine brain imaging for HER2+ and triple negative patients

use the guidelines!

If you are responsible for treating patients with advanced breast cancer, or are a patient trying to decide on the best treatment options, these guidelines are for you!

This text is a brief summary. The guidelines will be published in full in the Breast and online at www.abcräche.org

- TREAT PATIENTS ACCORDING TO GUIDELINES
- IN A MULTIDISCIPLINARY, SPECIALIZED TEAM, if possible CERTIFIED
- This is almost always COST-EFFECTIVE!
The management of ABC is complex and, therefore, involvement of all appropriate specialties in a multidisciplinary team (including but not restricted to medical, radiation, surgical oncologists, imaging experts, pathologists, gynecologists, psycho-oncologists, social workers, nurses and palliative care specialists), is crucial. (LoE/GoR: Expert opinion/A) (100%)
Every year 361,608 women in the European Union are diagnosed with breast cancer and 91,585 women die of the disease. 1 in 8 women in the EU-28 will develop breast cancer before the age of 85. Early diagnosis through population based mammography screening programmes together with care and treatment in specialist breast units improves both mortality and quality of life. The Declaration therefore calls for the following:

- Member States to implement nationwide breast screening, in accordance with EU guidelines
- Member States to provide multidisciplinary specialist breast units in accordance with EU guidelines by the 2016 deadline
- Member States to ensure that people with metastatic breast cancer have access to, and are treated in, an SBU and that their ongoing needs for care and psychosocial services are co-ordinated and supported by the SBU, as per EU guidelines
- The European Commission Initiative on Breast Cancer (ECIBC) project to deliver an accreditation protocol for breast cancer services by 2016; this protocol must ensure that mammography screening programmes and SBUs meet the requirements of the current EU guidelines and of the updated version of the EU guidelines, to be undertaken by the ECIBC in 2015
INEQUALITIES IN ACCESS TO CARE
Between countries but also within each country

Disparities in cancer outcomes (survival) across Europe

Figures 2: Age-standardised incidence (rates per 100,000 person-year) vs. age-standardised five-year relative survival (%) for cancers of breast (women), prostate, skin melanoma by European region. Period of diagnosis 2000–2007. Countries represented by dots.

INEQUALITIES IN ACCESS TO CARE
Between countries but also within each country

2 examples

A.S., 47 years-old, diagnosis of LABC HER2+ ER negative in Angola. Went to Namibia for treatment. Had mastectomy and axillary dissection. Started adjuvant CT but could not afford trastuzumab. Received AC. Could also not afford RT.

2 years later, relapse with LN and lung metastasis. Started a taxane + trastuzumab in Angola but, after 1 cycle, the hospital stock was over. Continued taxane alone, with progression of disease.
The worrisome situation of New Zealand
Figure 3: Survival time for metastatic breast cancer
Changes in survival through time

Table 3: Median, one and five-year survival after MBC diagnosis, for people diagnosed in each period

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<tr>
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<tbody>
<tr>
<td><strong>Median survival (months)</strong></td>
<td>10.6 (6.8, 19.9)</td>
<td>14 (11.4, 16.7)</td>
<td>18.8 (15.9, 21.4)</td>
</tr>
<tr>
<td><strong>One-year survival</strong></td>
<td>46% (34, 58)</td>
<td>54% (48, 60)</td>
<td>62% (58, 67)</td>
</tr>
<tr>
<td><strong>Five-year survival</strong></td>
<td>12% (05, 20)</td>
<td>11% (08, 15)</td>
<td>15% (11, 19)</td>
</tr>
</tbody>
</table>
Figure 5: Median survival after metastatic diagnosis by subtype

Table 4: Median survival after metastatic diagnosis by subtype

<table>
<thead>
<tr>
<th>Subtype</th>
<th>Median Survival (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Luminal A</td>
<td>27.3 (21.4, 30.6)</td>
</tr>
<tr>
<td>Luminal B1</td>
<td>15.9 (13, 20.8)</td>
</tr>
<tr>
<td>Luminal B2</td>
<td>24 (18.3, 28)</td>
</tr>
<tr>
<td>HER2 enriched</td>
<td>13.3 (10, 17.7)</td>
</tr>
<tr>
<td>Triple Negative</td>
<td>6.6 (5.8, 8.7)</td>
</tr>
</tbody>
</table>

PRIORITY! CAN EASILY BE IMPROVED!
## WHO ESSENTIAL MEDICINES LIST 2015
- Those for Solid Tumors

<table>
<thead>
<tr>
<th>Cytotoxics</th>
<th>Cytotoxics</th>
<th>Cytotoxics</th>
<th>Hormones</th>
</tr>
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<tbody>
<tr>
<td>bleomycin</td>
<td>docetaxel</td>
<td>irinotecan</td>
<td>anastrozole</td>
</tr>
<tr>
<td>calcium folinate</td>
<td>doxorubicin</td>
<td>methotrexate</td>
<td>bicalutamide</td>
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<tr>
<td>capecitabine</td>
<td>etoposide</td>
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<tr>
<td>carboplatin</td>
<td>fluorouracil</td>
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<td>leuprolelin</td>
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<tr>
<td>cisplatin</td>
<td>filgrastim</td>
<td>rituximab</td>
<td>tamoxifen</td>
</tr>
<tr>
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# Cost and Availability

Targeted therapies in Breast Cancer: Rest of World

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### Color Key
- **Free**
- **<25% cost**
- **25-50% cost**
- **Discount >50% and <100%**
- **Full cost**
- **Not available**
- **Missing data**

Reach to Recovery International Conference 2019
Metastatic breast cancer (formulary inclusion and cost to patients): Anti-Her2 therapy
ASIA-PACIFIC - METASTATIC BREAST CANCER: Cost & availability for patients

PERTUZUMAB

FULVESTRANT

Reach to Recovery International Conference 2019
The ABC community strongly supports the use of biosimilars both for treatment of breast cancer (i.e. trastuzumab) and for supportive care (i.e. growth factors). To be used, the biosimilar must be approved after passing the stringent development and validation processes required by EMA or FDA or other similarly strict authority.

(LoE/GoR: I/A) (90%)
We strongly recommend the use of objective scales, such as the ESMO Magnitude of Clinical Benefit Scale or the ASCO Value Framework, to evaluate the real magnitude of benefit provided by a new treatment and help prioritize funding, particularly in countries with limited resources.

(LoE/GoR: Expert opinion/A) (88%)
ACCESS/DISPARITIES: not just expensive medicines...

Pillar one: Pathology

Adesina et al, Lancet Oncol, 14(4), 2013
International Anti-neoplastic Medicines: Cost & availability - Tamoxifen

[Map of global availability and cost of Tamoxifen.]
In ABC Patient/Advocates are full and equal partners
Advanced Breast Cancer

Fifth ESO-ESMO International Consensus Conference

14-16 November 2019 | Lisbon, Portugal

Coordinating Chair: F. Cardoso, PT
Co-Chairs: G. Curigliano, IT - S.A. Mertz, US
Scientific Committee Members: K. Gelmon, CA
F. Penault-Llorca, FR - E. Senkus, PL - C. Thomssen, DE

The ABC5 guidelines will be developed by ESO and ESMO

The ABC5 conference and guidelines are endorsed by EUSOMA

The ABC5 conference is held under the auspices of OECI

with official representatives of ASCO

and is endorsed by ESTRO

RECEIVE UPDATES AT WWW.ABC-LISBON.ORG | ABCLISBON
BACK-UP
MAJOR LOBBYING/ADVOCACY/EDUCATION WORK NEEDED

Groundbreaking work done by
ABC DEDICATED ADVOCACY GROUPS

Most major Advocacy Groups have now specific resources for ABC pts

BUT

Limited, wide variation around the world, many still struggling to implement

ADVOCACY FOR AND WITH WOMEN LIVING WITH MBC
• Help define which outcomes are the most important to achieve from the patient perspective, both in early and advanced disease.

• In advanced disease, develop strong data regarding the real impact of PFS only benefits.

• Help develop better QoL tools, through use of PROMs and other (specially dedicated to advanced disease).

• Be involved in clinical trials from the beginning and help increasing the number of patients included in trials.

What evidence do stakeholders need from the patient community in order to make better informed decisions
Every advanced breast cancer patient must have **access to optimal cancer treatment and supportive care** according to the highest standards of patient centered care, as defined by:

- Open communication between patients and their cancer care teams as a primary goal.
- Educating patients about treatment options and supportive care, through development and dissemination of evidence-based information in a clear, culturally appropriate form.
- Encouraging patients to be proactive in their care and to share decision-making with their health care providers.
- Empowering patients to develop the capability of improving their own quality of life within their cancer experience.
- Always taking into account patient preferences, values and needs as essential to optimal cancer care.
- Patients should have easy access to well designed clinical studies, since these are crucial for further improvement in the management of ABC.

*(LoE/GoR: Expert opinion/A) (100%)*
Every advanced breast cancer patient should:

- Have access to the most up-to-date treatments and to innovative therapies at accessible Breast Units/Centers. *(LoE/GoR: Expert opinion/A) (100%)*
- Be treated in Specialist Breast Units/Centers/Services (SBU) by a specialized multidisciplinary team including specialized side effects management and a nurse experienced in the treatment of ABC. *(LoE/GoR: I/A) (100%)*
- Survivorship issues and palliative care should be addressed and offered at an early stage. *(LoE/GoR: Expert opinion/A) (100%)*
- A Quality Assurance Program covering the entire breast cancer pathway from screening and diagnosis to treatment, rehabilitation, follow up and palliative care including services and support for MBC patients and their caregivers, should be implemented by SBUs. *(LoE/GoR: Expert opinion/B) (100%)*