Addressing the unmet need in advanced breast cancer: a pan-European call-to-action
Making the invisible visible and improving quality of life

Worldwide, about 1.4 million women are diagnosed with breast cancer every year,1 making it the most common cancer in women.2 30% of women with early breast cancer go on to develop advanced disease, which is currently incurable.3

As recognised in international guidelines, the level of care and support available for early breast cancer (EBC) is not available to patients with advanced breast cancer (ABC).4,5 There is also a growing body of evidence that shows there is a high degree of unmet social and psychological need in ABC. Recent research indicates that women with ABC feel a sense of isolation and neglect from society in general, and more specifically from the non-ABC community.6

In 2013, in response to these unmet needs, the Here & Now campaign, an ABC disease-awareness initiative from Novartis Oncology, was established. The campaign aims to raise awareness of the realities of living with the disease and ultimately to improve the level of care and support available to patients.

In 2014, the campaign convened a Roundtable group of high profile multi-disciplinary stakeholders from the European breast cancer community to discuss the current status of ABC in Europe and agree a set of consensus points which now form the basis of this pan-European call-to-action.
Evidence to support the pan-European call-to-action

In order to address the unmet need and understand the true extent of psychosocial need and the perceived value of women with ABC, the Here & Now campaign has contributed to a growing base of ABC evidence which continues to inform campaign activities.

Key insights have been derived from the following three major pieces of Here & Now commissioned research:

- **Pan-European public awareness survey** which assessed the public’s knowledge and understanding of ABC
- **Patient and carer survey** which explored the personal and socio-economic impact of ABC
- **Pan-European healthcare professional (HCP) survey** which was launched at the roundtable meeting and assessed clinician and nurse perspectives on the unmet patient need in ABC. It also explored the needs and obstacles faced by HCPs working to diagnose, treat and manage the condition.

2202 members of the public across 11 European countries

158 patients + 146 carers; a total of 304 respondents, from France, Italy, Spain, Netherlands, Greece, Austria, Sweden, Denmark, Poland

330 HCPs across 9 countries: Belgium, Cyprus, France, Germany, Greece, Italy, Netherlands, Poland, Spain
PAN-EUROPEAN PATIENT AND CARER SURVEY

Results from the pan-European survey of ABC patients and carers demonstrate the significant personal impact of an ABC diagnosis:

- Over half of women with ABC felt they were perceived negatively by society.
- 37% stated they have lost confidence or a sense of personal identity since their ABC diagnosis.

The survey also highlighted the economic and socio-economic effects of the disease on women living with ABC:

- Of those women who were in paid employment (40%), half have had to make changes to their working life as a direct result of their condition.
- 56% of patients have experienced a decline in household income as a result of ABC, while 87% of patients said they have been forced to increase expenditure as a direct result of ABC.
- 40% of patients said they suffer psychological or physical problems as a direct result of changes in their financial situation.
- Following an ABC diagnosis, patients’ ability to contribute at home and in society fell by, on average, 50%.

In terms of areas for improvement, 79% of patients said it was necessary to improve personal well-being/quality of life and access to treatment, while 68% said it was important to improve access to and interactions with healthcare professionals.

PAN-EUROPEAN PUBLIC AWARENESS SURVEY

Key findings from the Pan-European Public Awareness Survey indicate that there is poor societal understanding of ABC and that less is understood about ABC than early breast cancer:

- 3 in 5 know someone who has, or has had, breast cancer; however 43% don’t know or are unable to correctly define ABC.
- 88% of respondents know that early breast cancer can be treated so the patient can become free from disease. However 77% of respondents either don’t know or think that ABC can be treated so that the patient can become free from the disease.

The results also reinforced the important societal contribution of the ABC patient population (i.e., postmenopausal and often 50+ years) with 56% of respondents stating that if the 50+ woman was not able to support them, it would negatively impact their life or those closest to them.

PAN-EUROPEAN HEALTHCARE PROFESSIONAL (HCP) SURVEY ON ABC

The pan-European Healthcare Professional Survey findings provided insight into HCPs’ perceptions of significant challenges faced in treating ABC patients, specifically relating to unmet psychological needs, lack of information on ABC, patient wellbeing, and consultation time:

- 83% of nurses and physicians say that ABC has a high impact on patients’ emotional wellbeing.
- 60% of physicians and nurses surveyed agree that patients with ABC often feel socially isolated.
- Just over one third of HCPs surveyed believe the greatest unmet needs for patients living with ABC are the availability of emotional and psychological support.
- Physicians and nurses say they do not have sufficient time with their ABC patients during appointments/consultations (physicians 47%, nurses 68%).
- 96% of HCPs surveyed agree that a multidisciplinary team approach improves the level of care for patients with ABC.
Here & Now ABC roundtable meeting

RATIONALE
Based on the significant gaps in patient care, societal understanding and HCP support relating to ABC that were revealed in the research, the Here & Now campaign ambassadors held a roundtable meeting in Brussels on 24 October, 2014 where they were joined by other experts from the breast cancer community. The aim of this meeting was to review the ABC evidence base and discuss the issues that patients encounter in today’s society, from which a call-to-action could be established to help drive access to optimal care and support across Europe.

OBJECTIVES
- **Gain an understanding of challenges** facing ABC patients across Europe in terms of care, support and access to treatment, exploring the commonalities and disparities between countries
- **Explore practical opportunities** for improving the situation of ABC patients in Europe
- **Understand the current barriers** that exist in terms of innovation in ABC
- **Secure support from leading experts** by shaping and defining a call-to-action for better outcomes for ABC patients in Europe

OVERVIEW
The group of leading clinical, patient advocacy, payer and health economy experts reviewed the evidence base and discussed the current barriers and challenges to supporting patients in Europe. They then heard presentations and participated in an in-depth debate on patient access challenges based on their varied perspectives. The final session, led by Dr Fatima Cardoso allowed for an interactive discussion, whereby the group consolidated all elements of the day and agreed on the areas of focus in order to improve current ABC care in Europe.

The resulting call-to-action found on the next page addresses key identified issues in partnership with the breast cancer community and outlines these critical priorities.
A Call to Action to Improve Patient Experiences and Outcomes in Advanced Breast Cancer (ABC) Across Europe

1. PUBLISH EXISTING ABC SURVEY FINDINGS

To: Raise awareness among the clinical community of the current unmet needs in the treatment and management of ABC and drive improved patient outcomes.

How can you get involved? Encourage qualitative and quantitative patient research so that collectively, we can continue to build the ABC evidence base. In order for the wider breast cancer care community to be aware of these insights and therefore identify and improve support and care gaps, we must all support the publishing of these findings and further insights in scientific journals and industry publications.

2. OBTAIN NEW ABC PATIENT QUALITY OF LIFE DATA

To: Provide greater understanding of the barriers facing ABC patients which can, in turn, inform and drive clinical and political change.

How can you get involved? We continue to learn more about the true impact advanced breast cancer has on a person’s life by uncovering new insights about the unmet need facing women and their families living with the disease. In our efforts towards this, we can also help support and leverage the important role that patient organisations play across Europe by seeking partnership opportunities for large-scale quality of life research, and subsequently publishing these findings in peer review journals to generate further exposure.

3. ADDRESS CLINICIAN CHALLENGES AROUND ACCESS TO A BROADER RANGE OF ONCOLOGY TREATMENTS, INCLUDING EARLIER ACCESS TO MEDICINES AND SUPPLY ISSUES

To: Improve the level of care for patients, bring about enhanced patient outcomes and support for HCPs treating ABC patients.

How can you get involved? Encourage and participate in discussions and debate around the complex issue of medicines shortages in European hospitals. It is these conversations that will lead to constructive dialogue between all members of the breast cancer community and thus, the exploration of practical solutions.
4. CREATE ‘PATIENT NAVIGATORS’ WITHIN EUROPEAN ONCOLOGY
MULTI-DISCIPLINARY TEAMS IN THE ABSENCE OF CLINICAL NURSE SPECIALISTS

To: Provide ABC patients across Europe with improved support, management and access to information about their condition.

How can you get involved?
Look to countries where this model is currently in place and thriving. Best practice sharing and continued professional development opportunities for specialised healthcare practitioners and those with an interest in ABC can help establish this important role within the multidisciplinary team.

5. SUPPORT THE DRIVE TO INCREASE THE NUMBER OF SPECIALIST BREAST CANCER UNITS IN EUROPE

To: Provide breast cancer patients in Europe with access to best standards of care.

How can you get involved?
Currently, specialist breast cancer units are a rare yet valuable resource that can be used as best practice models. We must also support and help amplify advocating organisations’ voices as they fight to establish such centres with dedicated and coordinated efforts on meeting the needs of breast cancer patients.
ABC roundtable faculty:

Here & Now campaign ambassadors

- **Dr Fatima Cardoso**, Director of the Breast Unit of the Champalimaud Cancer Center in Lisbon, Portugal
- **Gill Donovan**, Breast Oncology Nurse Specialist, Velindre Cancer Centre, Wales
- **Professor Michael Gnant**, Professor of Surgery at Vienna Medical University, Austria
- **Victoria Harmer**, Clinical Nurse Specialist in Breast Care, Imperial College Healthcare Hospital NHS Trust, England
- **Dr Konstantinos Papazisis**, Consultant Medical Oncologist, Euromedica General Klinik, Greece

Patient organisations

- **Elizabeth Bergsten Nordström**, President, Europa Donna
- **Karen Scanlon**, Head of Research & Evaluation, Breast Cancer Care, UK

Payors/health economists

- **Professor Fernando Antonanzas**, Economist, Department of Economics, University of La Rioja, Logrono, Spain
- **Dr Mathias Flume**, Head of Business Unit Prescription Management at the Kassenärztliche Vereinigung Westfalen, Germany
- **Professor David Taylor**, Emeritus Professor of Pharmaceutical and Public Health Policy, University College London, England

References

6. Cardoso F. Evolving psychological, emotional, functional, and support needs of women with advanced breast cancer: Results from the Count Us, Know Us, Join Us and Here and Now Surveys. 2015