



## Original article

# Challenges in optimizing care in advanced breast cancer patients: Results of an international survey linked to the ABC1 consensus conference

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## ABSTRACT

Until recently, many international guidelines have focussed on the treatment of early-stage breast cancer, with little emphasis on advanced-stage disease. To improve the management of advanced breast cancer (ABC), the European School of Oncology (ESO) established the ABC International Consensus Conference and Guidelines. Delegates from the first conference and additional groups selected by ESO were invited to complete a survey to identify current challenges and barriers associated with optimizing ABC management. 609 Respondents from 78 countries completed the questionnaire. “Lack of clear and applicable management guidelines” and “lack of high-level evidence for treatment options” were identified as key barriers to raising the profile of ABC and treating the disease. The survey also revealed a lack of multi-disciplinary treatment, specialized ABC nurses, and routine psychosocial support in clinical practice. Implementing high-quality guidelines could lead to better practice in the management of ABC by encouraging multidisciplinary treatment and patient-support initiatives.

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## Introduction

Outcomes are improving for patients with early breast cancer (EBC). Despite increased incidence, data over the last 60 years show that mortality from breast cancer has substantially decreased [1]. However, the evolution has differed between early-stage and advanced-stage settings: improvements in survival rates in EBC are measured in years, whereas in advanced breast cancer (ABC) they are typically measured in months. This discrepancy needs to be addressed. Patients with ABC make up one-third of the breast cancer population [2], and although recurrence rates following diagnosis of EBC are greatest in the first 3–5 years after primary therapy, patients are still at risk of recurrence for decades after [3]. Differences in the biology of the disease are likely to play a key role in the variation in survival; however, other issues such as different

treatment aims and lack of international consensus on the best standards of care may also be factors [4].

Although most physicians agree that a diagnosis of ABC is either at least as distressing or more distressing than a diagnosis of EBC [5], many patients with advanced disease feel isolated and believe that the media, healthcare professionals, and patient organizations prioritize early-stage disease [5,6]. A survey (the Bridge Survey) conducted in 2008 of more than 1300 women with metastatic breast cancer (MBC) from 13 countries showed that 52% of women felt that MBC received too little attention, and 48% thought that EBC received more attention than MBC [7]. The survey also found that women believed healthcare professionals, researchers, media, governments, and women with EBC do not pay enough attention to MBC, and that women would value more educational materials on MBC. This is consistent with the fact that, until recently [8,9], many of the main international guidelines on breast cancer have focussed on the treatment of early-stage disease [10,11]. Tellingly, a survey of 198 physicians conducted in 2006 found that while almost all physicians use clinical practice guidelines to aid treatment decisions for ABC, the vast majority would like them to be updated more frequently and to be more specific to different patient subsets [5].

Abbreviations: ABC, advanced breast cancer; EBC, early breast cancer; MBC, metastatic breast cancer.

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In recognition of some of the challenges associated with treatment of ABC and the shortcomings of available guidelines, the European School of Oncology (ESO) established a taskforce (ESO-MBC) in 2006 that published a set of 12 recommendations on ABC management [12]. These statements were later publically discussed at several European Breast Cancer Conferences (EBCC) in 2006, 2008, and 2010 [13,14].

Building on the momentum, ESO established the ABC International Consensus Conference series. The first meeting (ABC1) took place in Lisbon, Portugal on 3–5 November 2011. Approximately 800 delegates, including healthcare professionals and patient advocates, representing 64 countries worldwide, participated. The objective was to devise a series of guidelines for ABC, based on the most up-to-date evidence, which could be used to guide treatment decision-making in diverse healthcare settings globally [15]. All delegates, and some additional groups selected by ESO, were invited to complete a survey designed to collect information on ABC, including the availability of specific resources for treating patients and the guidelines followed by participants at that time. The survey was also designed to identify current challenges and barriers associated with optimizing the care of patients with ABC. Results from this survey were discussed at the second ABC International Consensus Conference (ABC2) [16] and are presented here.

## Methods

The survey, which consisted of 21 questions (Table 1), was initially opened to registrants approximately 2 weeks before the ABC1 conference, and was also available both during and immediately after the meeting. In addition, the survey was sent out to other groups after the meeting, including patient advocacy groups, The European Oncology Nurses Society (EONS) [17], The Breast Centres Network [18], and the e-ESO mailing list [18]. The differences between groups were analysed qualitatively.

The last response to the survey was received on 9 April 2012. Descriptive results of key questions are presented here. Results from the other questions are shown in the Supplementary tables.

**Table 1**  
Survey questions from ABC1.

Question number	Question
1	Sex
2	Country of residence
3	Profession
4	Primary location of practice <sup>a</sup>
5	How long have you been treating patients with breast cancer? <sup>a</sup>
6	Regardless of role what percentage of your patient-facing/clinic time do you focus specifically on ABC? <sup>a</sup>
7	How much of your patient-facing time is spent involved in clinical trials for ABC? <sup>a</sup>
8	Do you agree that generally the treatment of ABC is not as high profile, as early stage breast cancer?
9	In your opinion, why is treatment of ABC not as high profile, as early stage breast cancer?
10	What are the current barriers to optimal patient care in ABC?
11	For those barriers that you deem a significant or critical barrier, please specify how you think these could be overcome
12	Which guidelines do you follow at present for ABC? (Select all that apply)
13	Why would international consensus guidelines for ABC be useful? (Select all that apply)
14	How likely are you to implement the developed ABC guidelines?
15	Are guidelines such as the ones being developed at ABC1 likely to influence the availability of resources for the management of ABC in your country/Institution?
16	Do you have a specific MDT meeting for advanced breast cancer?
17	Do you have dedicated nurse specialists for ABC?
18	When is psychosocial support for patients introduced?
19	What other support facilities and services are available for patients with ABC?
20	What measures do you suggest to increase the implementation of the international consensus guidelines being developed at the ABC1 conference worldwide?
21	What measures do you suggest to increase the implementation of the international consensus guidelines being developed at the ABC1 conference in your country?

Unless otherwise stated, each question was open to all respondents.

ABC, advanced breast cancer; MDT, multidisciplinary team.

<sup>a</sup> This question was restricted to healthcare professionals who were treating patients with ABC at the time of the survey.

## Results

### Survey participant demographics

In total, 609 respondents completed the survey, representing 78 countries worldwide. Demographics of participants (Questions 1–3 and 5–7) are given in Table 2. Approximately 65% of respondents were from Europe. Most (69%) respondents were from high-income countries (as defined by the World Bank). Healthcare professionals made up 84% of respondents (physicians, 69%; nurses, 3%; other healthcare professionals, 11%); half of the physicians were clinical or medical oncologists. Nearly 5% of respondents were members of patient advocacy groups and around 12% of respondents were other nonhealthcare professionals, of whom around three-quarters were employees of pharmaceutical companies.

Of the respondents who were healthcare professionals treating patients at the time of the survey, 75% had been treating patients with ABC for at least 5 years and 40% had been treating patients for at least 15 years. Almost 70% of these healthcare professionals spent no more than 40% of their patient-facing time treating ABC and 59% spent no more than 20% of their patient-facing time participating in clinical trials for ABC.

### Views on current treatment practices in ABC

Of the 486 respondents who answered Question 8 (do you agree that generally the treatment of ABC is not as high profile as EBC?), 79.8% of them agreed. Reasons why respondents agreed (Question 9) are shown in Table 3. Mean scores were calculated for each reason put forward on a scale of zero (“not an issue”) to four (“a critical issue”). Although statistical significance was not assessed, there was a general trend for issue levels to be higher in poorer countries than in richer countries: the mean scores increased with decreasing World Bank income category (data not shown).

The two reasons for ABC having a low profile compared with EBC that respondents thought were most pressing were “lack of clear and applicable management guidelines” and “lack of high-

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