

## EUROPA DONNA: has strength in its heterogeneity

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### Abstract

EUROPA DONNA, a non-profit-making organisation, is a pan-European movement against breast cancer; it is a coalition that is active in 29 countries, each organised into national independent Fora. In each Forum, a postal survey was conducted between 2001 and 2002. A standardised questionnaire was used to collect information about Forum characteristics and activities, and perceptions of the adequacy of the local health service in relation to the prevention, diagnosis and treatment of breast cancer. Twenty-seven Fora (93%) participated in the survey. The results show the heterogeneity between the Fora in the services offered and activities in the different countries. The Fora also perceived a range of deficiencies in the prevention, diagnosis and treatment of breast cancer within their national health systems. These results highlight the importance of a coalition to establish a consensus among the Fora, and the need for coordinated initiatives in different European countries.

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### 1. Introduction

Breast cancer (BC) is the most common malignancy amongst women in Europe and the most common cause of death amongst middle-aged women. Currently, 321 000 new cases of breast cancer are diagnosed in Europe each year, resulting in 124 000 deaths [1,2]. Europe is a continent composed of different cultures, languages and traditions and the European breast cancer picture tends to reflect this complexity [3]. Emula-

tion of the American or Australian advocacy experience in Europe is therefore unrealistic.

EUROPA DONNA,<sup>1</sup> a non-profit-making organisation, is a pan-European movement against breast cancer [4]. It is structured in accordance with national breast cancer objectives, whilst helping to provide a focus for the exchange of information and experience within the European framework and it also serves as a driving force for combined action among Fora or among members. EUROPA DONNA represents the concerns and interests of European women before local

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and national authorities and government, drawing attention to improvements that are needed in essential programmes and services in the fight against breast cancer. We are a coalition of individual women and associations involved in the fight against breast cancer (BC associations), active in 29<sup>2</sup> European countries, each organised as an independent national Forum,<sup>3</sup> working autonomously within the European framework. Each national Forum, chaired by a national Board and represented at the European General Assembly of EUROPA DONNA, selects the objectives it wants to pursue from the coalition's 10 goals [5].

This survey was carried out to collect information about the characteristics of Fora and their activities, and how they perceive the adequacy of local health services relating to the prevention, diagnosis and treatment of breast cancer. An additional aim was to assess the relevance of EUROPA DONNA's 10 goals. The survey aims to stimulate Fora to commit themselves to common aims and to share historical, social and personal experiences.

## 2. Materials and methods

On the basis of a previous Italian Forum survey [6], a preliminary questionnaire was drafted. The draft was discussed and tested among the members of the Executive Board of EUROPA DONNA and then modified. The final version of the questionnaire, with a total of 35 questions, explored the following areas of interest:

- *Structure and organisation of the local Forum*: 15 questions covering the level of independence of the centre, the type of collaboration, and the services offered;
  - *Composition of the local Board*, one question on age, background, and breast cancer history of the local Board members;
  - *Perceived relevance of the ten EUROPA DONNA goals*: one question regarding the importance of the goals, in light of local experiences, the socio-economic situation, and the organisation of health-care, in order to improve conditions and address issues related to breast cancer in the responder's country;
  - *Opinion about national health system services*: 15 questions seeking a description of the health system and any deficiencies in early detection, diagnosis, assistance and follow-up;
  - *Information on breast cancer*: three open questions not presented in this article.
- Most of the questions had closed response options, but space was also provided for respondents to

provide further comments. No specific training was organised, but the study was exhaustively presented and discussed during the pan-European conference of EUROPA DONNA. Detailed written instructions were given in the covering letter which also reported the aims of the survey.

In February 2001, each Forum received a letter describing the survey and a copy of the questionnaire, with instructions for completing it. A second, updated questionnaire was sent during 2002. Letters, phone calls and e-mails were sent to Fora that did not return the questionnaire. Twenty-seven of the 29 Fora sent back the completed questionnaire, allowing data analysis on 93% of the countries represented by EUROPA DONNA.

Data were analysed using the software SAS<sup>®</sup> System statistical package. Reports and ratings were described using descriptive statistics such as means, medians and proportions [7].

## 3. Results

Table 1 sets out seven selected questions regarding the structure and organisation. Fora had been established for a mean of 7.2 years, had a mean of 1.72 'office' rooms, nine of the Fora (33.3%) coordinated, on average, the work of 1.8 employees, helped by a large number of volunteers. 6.1% were open 5 days a week. Most of the Fora have their own centre. Moreover, 92% (23/25) Fora had some type of regular collaboration (consultancies) with breast cancer specialists; 16 had consultations with surgeons, 20 with oncologists, 18 with psychologists, 13 with radiotherapists, 10 with psychiatrists, 12 with gynaecologists and 11 with other specialists. Most of the Fora who responded (75% (18/24)) have membership dues, and 24 received funding through donations, pharmaceutical companies' sponsorship for joint projects, medical or other foundations; only a few mentioned government or state support.

Table 2 describes the services offered regularly by Fora and their members. Information, training courses and psychological assistance were the most frequent services offered, and local members also offered direct practical assistance for prostheses. This is not surprising considering that at the local level members of breast cancer associations are often involved directly with patients.

Table 3 describes the composition of local Boards. Generally, the women involved are young (average age of around 50 years), including some breast cancer survivors, and have different backgrounds. It is interesting to note the high percentage of women with a medical or scientific background participating at the local Board

<sup>2</sup> In May 2003, the 30th Forum joined EUROPA DONNA.

<sup>3</sup> Forum, literally from Latin: market place, town square; plural Fora.

Table 1  
Selected questions put to the 27 Fora who participated in the survey

Question	Answer
When did the Forum officially establish its activity in your country? (24)	Mean 7.2 Range 3–10 (1993–2001)
How many rooms does your Forum centre/office have? (18)	Mean 1.72 Range 1–3
How many employees work in your Forum? (9)	Mean 1.8 Range 1–4
Does the Forum have daily opening hours (from Monday to Friday)? (18)	Yes 61.1%
Does your Forum have an independent centre/office? (24)	Yes 62.5%
How often do you elect a new Board? (21)	
•Every year	19.0%
•Every 2 years	23.8%
•Every 3 years	33.3%
•Every 4/5 years	23.8%
How often does your Board meet? (20)	
•Every month	45.5%
•Every two months	22.7%
•Other	31.8%

In brackets, the number of respondents to each question; percentages are calculated using the total number of valid answers to each question.

Table 2  
Services offered regularly by the Fora and their members

	Number of Fora offering this service	Number of members associated with a Forum offering this service
Psychological assistance	10	11
Physiotherapy/Rehabilitation gymnastics	4	8
Lymph drainage	2	6
Organisation of courses: gymnastics, yoga, swimming	5	7
Assistance for the procedural aspects of prosthesis, requests for invalidity, prosthesis fitting	7	14
Training courses for volunteers	11	9
Promoting breast self-examination	9	12
Dietary education	5	10
Medical-legal assistance	3	4
Library	5	6
Information and printed material	19	14
Entertainment (concerts, etc.)	7	8

Table 3  
Fora: composition of the boards of the local Fora

	Mean age (range) (years)	Breast cancer survivor (%)	Medical or scientific background (%)	Psychological background (%)	Other type of background (%)
President	50.95 (36–72)	57	40	8	52
Vice-President	51.28 (28–70)	48	46	–	54
Treasurer	52.72 (33–77)	57	9	–	91
Members*	49.20 (23–70)	44	37	8	55

\*Members are analysed all together; results refer to a total of 113 members.

level: this is evidence of a growing level of professional qualifications among members involved in the coalition.

All 10 goals of EUROPA DONNA were considered to be of general importance. The mean rating ranged from 4.86 for the goal ‘To emphasise the need for

appropriate screening and early detection’ to 6.61 for the goal ‘To campaign for provision of optimal treatment’. When countries were divided into ‘European Union countries (EUc)’ and ‘Non-European Union countries (NEUc)’, not surprisingly, goals such as ‘To

Table 4  
Opinion on the relationship with the national health system

	All countries (% yes)	EU countries (% yes)	Non-EU countries (% yes)
Do screening programmes exist for the early diagnosis of breast cancer in your country?	76.9	100	53.8
Is this programme available for all women in your country?	42.3	46.1	38.4
Does your Forum collaborate directly in these programmes?	43.4	50.0	36.6
Has your Forum participated directly in research, for example: clinical trial, survey, epidemiological studies, literature review etc?	43.4	63.6	25.0
Are there deficiencies in your country's health system regarding the prevention/early detection of breast cancer?	76.1	100.0	58.3
Are there deficiencies in your country's health system regarding the diagnosis of breast cancer?	72.7	80.0	66.6
Are there deficiencies in your country's health system regarding the assistance/care of breast cancer patients?	86.3	100.0	72.7
Are there deficiencies in your country's health system regarding the follow-up procedures of breast cancer?	71.4	88.8	58.3

Percentages are calculated using the total number of valid answers to each question. EU, European Union.

ensure quality supportive care throughout and after treatment, to demand regular quality assessment of medical equipment, to acknowledge good practice and promote its development, and to promote the advancement of breast cancer research' were considered more relevant in NEUc than in EUc. Among EUc, one of the most relevant goals was 'To promote breast awareness'.

As expected, the organisation of national health systems varies considerably, but, in general, basic care is guaranteed. Opinions on national health systems are reported in Table 4. Screening programmes are not available in all European countries represented by EUROPA DONNA, and early detection programmes are not available for eligible women in more than half. Ten Fora (43.4%) directly participate in research work, in particular in quality of life studies or as a member of a research group.

Most of the Fora complained about deficiencies in their health system. Only about a quarter reported no deficiencies in their country's health system regarding the different phases of diagnosis and care. These results varied amongst EUc and NEUc. As shown in Table 4, screening programmes are established in all of the EUc, compared with only 53.8% of the NEUc. However, the screening programme is not available for all women in all the countries. The EUc always reported higher percentages of deficiencies in their health systems, but these differences were not statistically significant.

#### 4. Discussion

EUROPA DONNA is a well-known European opinion movement. Its scientific activities as a partner of

major scientific societies [8], and political work as a promoter of initiatives with the European Parliament [9] testify as to the weight of this consumer group and the impact of its initiatives. This survey illustrates the variety and strength of the coalition. Twenty-nine Fora belong to EUROPA DONNA, each with a different history, economical and political situation, facilities and access to healthcare.

The Fora reported a generally unsatisfactory picture of many aspects of prevention, diagnosis and treatment of breast cancer, as shown by their opinions on deficiencies of healthcare. Despite differences between EUc and NEUc in our survey, the European breast cancer survival rate is not significantly better in some countries than in others, but varies at the regional level in certain countries and even from hospital to hospital. Similar disparities exist in terms of access to standard diagnostic and treatment facilities [10,11].

This survey has some limitations: most but not all the Fora answered the survey, and questionnaires arrived at the Coordination Center after several reminders; more than 1 year was necessary to collect very simple information on Fora organisation and activities. There are several possible explanations for this. Firstly, Fora are kept busy coordinating local activities, such as encouraging women with breast cancer to take part in coordinated activities, organising awareness campaigns, promoting and participating in early diagnosis or screening programmes and quality of care, organising lobbying and partnerships with the medical and scientific community and, finally, fund raising. Considering the burden of these activities and the restricted local resources, it is perhaps not surprising if little attention is paid to participating in a survey. Secondly, not all the

Fora are used to documenting their routine activities in detail or to collecting data through a questionnaire and might not have thought the questionnaire was important.

The EUROPA DONNA coalition can make a difference by lobbying for change [12]. As a consequence, a non-partisan, all-party European Parliamentary group on breast cancer (EPGBC) was formed in September 2001 to raise awareness of breast cancer issues in the European Parliament and to ensure that this disease is on the European healthcare agenda. In June 2002, EPGBC and EUROPA DONNA invited the members of the European Parliament and the European Commission to attend an exhibition in the European Parliament ‘Breast Cancer in Europe Today’. The presence of more than 200 participants at this event shows the increasing concern about this devastating illness in Europe. Recently, Karen Jöns, chair of EPGBC, stressed that all European women must be assured of equal access to quality screening, diagnostic, treatment and care facilities, and again, urged the implementation of European guidelines [13,14]. A report on breast cancer with 58 amendments [9] was prepared by the EPGBC and voted during the Plenary Session of European Parliament in June 2003.

In conclusion, in recent years the involvement of consumers in the discussion of health issues has been widely debated in the literature [15–17] or in *ad hoc* web sites [18,19], and an increasing consensus is encouraging partnerships between consumers, patients, care-providers and the social-political system to share the responsibility for public health. EUROPA DONNA exemplifies these trends in the field of breast cancer. Its activities, overall and at local levels, its partnership and collaborations, and its considerable achievements to date, all illustrate the strength of this European coalition.

## 5. Conflict of interest statement

We have no conflict of interest to declare.

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