Guidelines for voluntary organizations working in multidisciplinary breast centres

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Introduction: Europa Donna Italia has drawn up some Guidelines to support Voluntary Associations (VA) in carrying out activities in individual territories and as member of the national network in order to multiply the strength of associations and so that women can be cured in multidisciplinary centres, progressively conforming to Eusoma Requirements (Guidelines on the Requirements of a Specialist Breast Centre).

Method: The Guidelines define a common platform for a proper understanding of the interaction system and knowledge between VAs operating in BC, specialists of Breast Centre (BC), political and territorial authorities involved in the healthcare system and women who are welcomed in BC. Only knowledge, reliability and transparency can help to build solid foundations among all actors in order to promote the best possible care for woman and a support network for patient and her family.

Results: The Guidelines identify the minimum requirements necessary for the development of Voluntary Associations acting in Breast Centre and that jointly build a regional / national Advocacy that can significantly change breast cancer treatment policies and ways of assisting women.

KEYWORDS
- ✓ Europa Donna
- ✓ Breast Centre advocacy
- ✓ Advocacy Guidelines
- ✓ Eusoma
- ✓ Multidisciplinary approach
- ✓ Advocacy Education
- ✓ Advocacy Information
- ✓ Advocacy good practice

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Premises

In order that all European citizens can rely on the best pathways for early diagnosis and breast cancer treatment, the international coalition **Europa Donna** (www.europadonna.org), which brings together 47 Countries, has been pursuing its advocacy action for more than twenty years so that Breast Centres (BC) are realized with a multidisciplinary approach, meeting the requirements established at European level for breast centres (see European Recommendations 2003-2006-2015 and the Guidelines of ***European Society of Breast Cancer Specialist - Eusoma).***

Europa Donna Italia (EDI) works in synergy and in support of Voluntary Associations working at territorial level in favor of women for the prevention and treatment of breast cancer. In its activity of promoting breast centres, it collaborates with Senonetwork Italia onlus, the network of Italian breast centres, which in turn has contributed to the drafting of Guidelines issued by the Ministry of Health.

Since the Ministerial Guidelines give a specific role to the Voluntary Association within the breast centre, EDI has decided to prioritize the development of culture and training dedicated to the volunteers (males and females) of the Associations operating in centres: from this classroom, communication and management experience, from the meeting between volunteers and clinical specialists, EDI has come up with a further need: to create a summary document containing the good practices developed in Italy by the Voluntary Associations operating in breast centres and defining a homogeneous and transparent approach for them.

From this collective and widespread work, born the Guidelines for Voluntary Associations of Patients that operate for the prevention and treatment of breast cancer within the breast centres.

The document in addition to the good practices developed by the Voluntary Associations (VA) declines the basic requirements that a Voluntary Association must support to ensure that the promoted activity has a homogenous and transparent approach and that the VA is recognized as reliable and stable by all interested parties starting from women and breast centres specialists: new areas of collaboration are identified on knowledge and respect for roles.

The recommendations and requirements contained in the Guidelines are addressed to all Associations and provide minimum standards for resources, skills and activities to be undertaken by volunteers in order to contribute to a high level of care for women, in collaboration with breast specialists operating in a multidisciplinary manner with resources and staff dedicated to women from diagnosis to follow up.

The VA interaction within a BC is based on the sharing - between VA, the Health Care Directorate of the host structure and BC Coordinator - of humanization of care as founding principle of clinical and assistance activity.

From a methodological point of view, it was crucial to define a common communication matrix (terms and definitions related to VA in Breast Centre) and establish **constituent elements of VA** to support the development and self-awareness of individual VA, the main areas of intervention typical of a VA operating in breast centre.

Among the basic elements to encourage a trusted and transparent relationship between volunteer - woman / patient and BC specialists, are identified:
- *a formal constitutive act*, *in accordance with national regulations of the own Country of origin,*
- *a statute, that contains all the rules regulating the life of the association*: the purposes pursued and the activities that can be carried out, the constituent elements of the VA itself (association bodies, the role of associates and responsibilities), the ways of fundraising and dissolution

- *an assessment of sustainability, even economic, compared to the activities carried out annually*
- *an ethical code and a mission*, known and accessible to all volunteers.

To affect at national / regional level, the single VA should adhere to wider network Advocacy, with the ultimate aim of contributing to the development of healthcare institutions that ensure all women:

- prevention and adequate information to gain access to prevention;
- qualified and accessible early diagnosis programs;
- effective, personalized care, respectful of women's integrity and ensuring the best possible quality of life;
- assistance throughout the entire course of the disease within breast centres according to the European recommendations adopted by individual States;
- access to rehabilitation services, which can promote psycho-physical recovery and reintegration into the own daily and working context.

1. The Association in Breast Centre

In the Guidelines, EDI has chosen to prioritize how the VA perform information activities about the modalities of access to services and performances, the therapeutic pathway and the management of side effects within BCs.
Volunteers help patients concretely during the treatments, create listening points to improve the taking charge of patients by BCs and interact with healthcare institutions / BC to claim the right to quality of care.
Volunteers accompany the woman during her pathway in BC with a presence as organized as possible, so that the patient does not feel alone.
The VA operating in BC watches that BC is a true multidisciplinary reality with professionals and structures as defined in the guidelines of ***European Society of Breast Cancer Specialist (Eusoma).***
The VA promotes the certification of Breast Centres, as further guarantee of ***quality for women***.
Operationally, some requirements are summarized to consolidate the ***player*** status of VAs in BCs.

1.1 The organizational structure of the Association

1.1.1 *The Constitution of the Association and its specific objectives in favor of women*
The VA must:
- make available its own ***Mission*** (main purposes of action) in writing to all interested parties (e.g. through a website or Facebook page or in a brochure).
- be clear about how to stay active: the minimum number of volunteers for carrying out the activities, the minimum skills that must be present, the minimum funds for the operation, etc.
- networking with other VAs to optimize resources by sharing national battles, tools (e.g. publications), key professionalism (e.g. volunteers with specific health skills, lawyers, labor lawyers, etc.)
- to communicate, according to the ***Principles of Transparency***, the own activities, including economic ones (by publishing the results of the activities on the own website or other similar channel).
- to maintain, with the aim to consolidate the own self-awareness, ***relevant Data and Information about the activities carried out***, possibly assessing their evolution over time (e.g. number of volunteers involved in the VA, number of women welcomed each year, funds raised for initiatives in support of women / patients, number of training / information activities carried out in favor of patients

and number of participants, number of projects / events developed and / or supported with relapses in favor of women).

1.1.2 The interlocutors of the Association

Each VA, in the face of its own identity, and beyond the BCs, must identify all the interested parties with whom it must relate and understand where to channel its energies.

As far as political and health aspects:

- at Regional level
- at level of Social-Health Territorial Company
- at city level

considering always other contexts too:

- other VA present in local area to make local network
- charitable institutions, financers and sponsor to activate initiatives and fundraising
- communication companies and media as resonance boxes for initiatives and proposals on the territory.

1.1.3 Members of the Association: identification of the intervention area referents. Training and awareness of members.

Every VA, to achieve maximum performance, should ***"map"*** the skills of its own volunteers: they are the wealth of the VA and the characteristics of volunteers in the development of activities should be exalted; for this reason, knowing the working skills and the profession performed, talents and attitude and even the eventual managerial skill, enhance the action of the VA and the passion of volunteers, also facilitating the transfer of strength to activities in favor of women.

The members of the association should ratify the strategic roles and establish within the VA at least one representative for each area of intervention (see section 2).

In order to reinforce the awareness of VA members, it is crucial to provide for moments of confrontation and coaching, not only for the new ones involved in the association but for all volunteers and take advantage of all the information / training opportunities also in line with the roles covered and the activities carried out within the VA.

1.1.4 Instruments, places and communication at the service of VA action

The VA should, in order to facilitate its own identification by all the interlocutors and above all by women:

- establish a ***space,*** with minimum comfort and privacy criteria, to meet the woman and / or the patient. It would be preferable a fixed and identifiable space, but if this is not possible, it will be necessary to define minimum privacy and ***well-being requirements for the woman-patient***
- identify volunteers with a tag and any other ***identifying elements*** (e.g. a uniform and / or a distinctive sign)
- define and communicate to members of the VA, attendances and general limits to be respected as regards the regulation of ***privacy and safety in places where it operates***. These elements must be calibrated according to the type of action and activity of the single VA
- formalize a simple and effective document (e.g. vademecum) to be delivered / made available (also *online*) to both VA members and interested parties to make clear the way of acting in BC.

2. Areas of intervention in favor of women of Voluntary Associations

2.1 Patient area

The Patient Area has two hubs for the interaction between VAs and women suffering from breast cancer: the correct information and services / supports that the VA can provide to patients.

2.1.1 Information

Among the possible areas of action, the VA must consider ***the communication*** by channeling the resources for making available, through volunteers and / or communication tools (web, Facebook, etc.) some:

- information on how to access services and performances of Health Services and BC
- information on prevention studies
- information on clinical trials and the relative participation of women in optics of innovation in treatment and diagnosis
- communication services by desk, identifying for such activities the volunteers adequately trained and providing adequate support materials: brochures, leaflets, videos, access to pre-verified websites, etc.
- listening times in synergy with Health Services and / or BC to improve the quality of the taking charge of patients
- detection service of satisfaction level of BC services compared to the performances offered in order to assess the perceived quality.

2.1.2 Assistance to women

The VA, based on its goals and its own *identity*, must be able to define and choose where to channel resources to develop specific women's assistance activities.

To achieve this, the VA should be able to identify the priority needs, considering the type of women-patients, and the relative families, health and social assistance services of the territory, the socio-economic territorial situation in which it operates.

Among the services promoted by VA in support of women, the following have been identified by way of example but not exhaustive:

- support for psychophysical recovery during and after patient's disease: diet, adequate and useful physical activity, and proper *lifestyle*; but also services for the treatment of lymphedema, for arm / armpit rehabilitation, for the treatment of chronic pain, and so on.
- support for woman in communication with BC specialists
- transport service from home to the BC for treatment cycles (direct service or stipulation of convenience conventions and reduced rates)
- availability of professionals (e.g. psychologist, sexologist) of support to patient and / or to family (partner, children, parents, etc.)
- assistance as regards to information and advice on: wig for alopecia deriving from drugs, *camouflage* for alopecia imperfections, underwear with insertion of prosthesis for mastectomized women without possibility of reconstruction
- cultural mediation for patients and foreign families.

2.2 Interaction Area with Breast Centre

The VA interaction within a BC is based on the sharing - between VA, the Hospital Directorate and BC Coordinator - of humanization of care as founding principle of clinical and assistance activity.

The active VA within a BC must evaluate the interaction modalities with all specialists of BC. Depending on the institution where BC exists (public or private body, hospital or clinic, foundation, etc.) the VA must identify the correct modalities of relationship and synergy in order to contribute to a better access to the healthcare system by women.

2.2.1 Accreditation of the AV

To establish a clear relationship with the institution in which the BC resides, the VA must know and respect its organizational system, then it must identify the correct procedures to be accredited at the Body (Contact with General Directorate, Health Care Directorate, etc.).

Once accredited at central level by the Body, the VA can then interact with the Coordinator of BC defining together modes and times to meet other BC specialists and start the collaboration.

Among the first significant achievable goals there are:

- identification of one or more physical places within the BC where VA can operate and meet women;
- identification of a privileged referent for the relationships and co-ordination between BC specialists and VA (e.g., breast nurse, psycho-oncologist, etc.) consistent with goals shared with the BC.

2.2.2 Common objectives

To increase the synergy between VA and BC, annually it is necessary that:

- VA and BC share the commitment to ensure the quality of care
- is defined at least one common goal to be achieved, defined according to patient and / or BC needs (e.g. fundraising for the purchase of an electromedical device, support the BC to promote the continuity of action of data manager, etc.)
- the goals achieved and / or suspended of the previous year are assessed
- a training / informative time is carried out for volunteers by BC. In this way, the VA can acquire useful knowledge to understand what are the therapeutic paths in place as well as possible updates of service by activating new pathways for the different types of breast cancer and the various patients afferent to the BC.

2.2.3 Performance data of BC

The VA, at least once a year, thanks to the enshrined agreements, must receive from the BC some data that give evidence of how the group of specialists pursues the goal of transposing the patient's needs and monitoring her health care path.

The data that the VA must consider is:

- Number of new cases of breast cancer treated by BC in the year (at least 150)
- Confirmation of the presence and activity of at least 1 dedicated Breast Surgeon (i.e. devoting at least 50% of time to breast disease)
- Confirmation of the presence and activity of at least 1 dedicated Breast Radiologist (i.e. devoting at least 50% of time to breast disease)
- Confirmation of the presence and activity of at least 1 dedicated Pathologist (i.e. devoting at least 50% of time to breast disease)
- Confirmation of the presence and activity of at least 1 dedicated Medical Oncologist (even in convention but dedicating at least 50% of time to breast disease)
- Confirmation of presence and activity of at least 1 dedicated Radiotherapist (even in convention, but dedicating at least 40% of time to breast disease)
- Confirmation of the presence and activity of BC Clinical Coordinator
- Confirmation of the presence and activity of at least one breast nurse
- Confirmation of the presence and activity of data manager
- Confirmation of the presence and functionality of a data collection database of BC

- Confirmation of MDM performance before and after surgery
- Woman's waiting time from first access to first therapy

In case of ***BC Certification***, the VA does not need to consider the above items since quality assurance is supported by certification.

2.2.4 Return Information of patients and of VA towards BC

The VA returns to BC, at least once a year, the information and needs gathered by patients they have met and at the same time provides synthetic evidence of volunteering action performed.

In this sense, the VA could develop, in agreement with the BC, appropriate tools (satisfaction questionnaires, individual interviews, etc.) or alternatively give women some questionnaires prepared by the BC

The VA may also apply to BC to support data processing, too.

It would be desirable for the VA to provide the BC with data on:

- number of women welcomed in the year
- time spent by volunteers in the year
- purchases made in support of the BC
- number of training / information activities carried out in favor of patients and number of participants
- funds collected and spent in favor of BC
- number of projects / events developed and / or supported with relapses in favor of women and the BC (e.g. support for BC operational quality through: *Training courses for BC members, promotion of Interlaboratory Quality Controls for Pathological Anatomy, BC Certification, etc.*).

2.2.5 Relational / operational modes of VA in relation to women's needs in BC

One of the prerogatives of the VA is to be formed predominantly by women who have already undergone the course of the disease, have faced breast cancer and know what it's like to face this experience at all stages.

From this collective consciousness, the VA must:

- always agree its own activity with the BC coordinator and all the health personnel involved, while respecting the skills of the operators. In addition, the presence of the VA or its representative must be welcomed by the patient and by her family network
- ensure the presence in organized and structured form, where appropriate with defined attendance shifts
- ensure the presence, according to the own resources, for women in charge, at all stages of the patient's path, having as rule that the presence of the volunteer must be functional to the patient, thus making her able to express freely also the discomfort, fears and anxieties
- create a ***Listening Point*** within the BC. It must be a physical site, set up in a suitable space, easily accessible and appropriately reported in the department and places where patients are involved, both before and after surgery and during follow-up. It would be desirable it was equipped with communication tools including a dedicated telephone line. The VA will have to agree with the BC coordinator to define days and timetables of patients reception. Volunteer attendance schedules must be organized
- be a ***Presence along the path of patient.*** The phases in which the VA could side with the woman are: communication of diagnosis, pre-hospitalization, hospitalization / hospital stay, oncological DH and Radiotherapy, Follow up; at the same time, the VA member, if required, can accompany all BC specialists in the path based on expressed needs and availability.

2.3 Institutional Area

The AV, in any context it operates, may and must try to have impact at institutional level (territorial, hospital / university within Screening Services, Breast Diagnostic Centres, Breast Centres, etc.) on prevention programs and diagnostic - therapeutic pathways in breast field.

The VA should be able to:
- foresee, at least every 2 years, the promotion of awareness-raising events / information at territorial level about women's needs and rights and scientific updating in breast field
- promote the presence of VAs in Ethics Committees for Research activity
- promote healthcare exemption for women at all stages of the disease, including follow-up and surveillance for high-risk women
- identify among volunteers of the VA at least 1 representative of women-patients who follows at ***territorial level*** the ***health policies*** related to the prevention and treatment of breast cancer
-identify among the volunteers of the VA at least 1 representative of women-patient who maintains contacts with the ***national coordination*** of VA to know and promote at ***national level the policies of breast cancer prevention and treatment***
- promote the right of all women to reintegration into the world of work during and after the disease
- promote practical and political collaboration between basic medicine services and breast services
- participate with the own associates, at advocacy level, in national institutional boards to request and ensure the fairness of prevention and diagnostic and therapeutic offer throughout the national territory
- participate with the own associates, at advocacy level, in teams of experts to evaluate and verify the quality of pathways, structures, technologies to protect and safeguard patients by defining appropriate assessment indicators.

2.4 Economic area

The VA, in any context it operates, can and must properly manage the financial aspects of the association in absolute transparency.
In particular in the management of:
- associates' fees
- projects funded by public and / or private bodies with accurate and correct financial reports and always on the basis of transparency, by submitting to funders the documentation and objective evidences of the activities performed
- sponsorships received from Bodies ethically operating in health and pharmaceutical fields and in accordance with the European guidelines dictated by EFPIA
- donations received
- donations to be made in favor of health institutions (e.g. BC or screening centres)
- fundraising and self-financing activities

For the economic area, the VA must have at least one dedicated administrative and well-trained figure or support advice.
In terms of credibility towards women and interested parties, the accounting management is crucial and must always be carried out:
- the reporting with annual publication of budgets of collection and expenditure of projects carried out, size and modalities of use of funds
- the control of use of funds by third parties
- the monitoring of costs / benefits of investments made based on economic availability.

3. Conclusions

The application of minimum organizational and transparency requirements set out in Europa Donna Guidelines promotes the VA and amplifies the positive impact of VA action for women, Breast Center professionals and institutions that have to meet the needs of women suffering from breast cancer.
The document in the integral form may be:
- adopted in partial or full form. If followed in full form, it may be subject to certification and / or monitoring on a voluntary basis by Voluntary Associations
- used as source of inspiration for the organization of the individual Association and / or for organizing a Network with shared principles
- used as a tool for presenting the VA to a BC, Governmental Structures and Health Policies, etc.