

SEPTEMBER 2020

# EUROPA DONNA 2020 SURVEY



THE CURRENT STATE  
OF BREAST SERVICES  
IN EUROPE

## 02 OVERVIEW:

In 2020, EUROPA DONNA – The European Breast Cancer Coalition has undertaken a survey project to provide a snapshot of the current state of breast services in Europe from the perspective of patient advocacy organisations. The following is a report on the survey results.

Fifty-two questions were posed, divided into five sections:

- Your country and breast cancer care
- Mammography screening and diagnosis
- Specialist Breast Units
- Metastatic Breast Cancer
- Miscellaneous, including Covid-19/cancer care

## CONTEXT AND DIAGNOSIS:

The survey was conducted from June through August and we received one response per country from breast cancer advocacy leaders representing Europa Donna national groups in the following 34 countries (24 of which are European Union countries): **Albania, Armenia, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Ireland, Israel, Italy, Latvia, Luxembourg, Malta, Monaco, the Netherlands, North Macedonia, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, and Ukraine.** The respondents all reported that they hold one or more leadership positions in their organisations, including National Representative, National Delegate, board member or member of a scientific committee.

It is important to note that the data reported here only reflects the knowledge and personal experience of the individual advocates who responded.

Questions 1 through 3 asked respondents to give their name and country, their role within their Europa Donna forum and to give consent to publication of the information they provided (all gave consent).



## 03

## YOUR COUNTRY AND BREAST CANCER CARE (QUESTIONS 4 – 19)

According to the survey responses, healthcare in the above-listed countries is largely set up on the national public level (79%), while 21% are organised on the regional level with national control and 9% organised on the regional level (respondents were able to choose more than one option). Breast cancer care is mostly provided by public health facilities in 53% of cases, and by a mix of private and public facilities in 47% of responding countries. In 84% of responding countries, all costs for diagnostics, treatment and therapy for breast cancer care are paid for by the public health system. In many of the remaining countries, some, but not all, of costs are covered (e.g., Albania, Romania, Ukraine) or there is a compulsory insurance system that pays all patient costs (e.g., Germany, Switzerland, Slovenia). Just over half of responding countries (52%, including Italy, Greece, Latvia, Ukraine) reported that in some cases such as genetic or genomic testing, certain diagnostic tests, etc., some or all costs must be covered privately. An impressive 76% of respondents claimed that the cost of supplementary aids, such as wigs and bra prostheses and lymphatic drains in follow-up care are reimbursed, at least in part, by their health system. **However, when breast cancer care is provided in private structures, only 38% responded that all costs are covered by their national health or insurance system.**

**Fifty-nine percent reported that they do not have a committee/advisory board/group in their national parliament/government, such as a Ministry of Health, that deals with breast cancer; this point is an area for potential advocacy development in many European countries.**

**Of the 24 European Union member countries that responded to this survey, only 12 reported that their national parliament has agreed to implement the European Parliament Resolutions of 2003 and 2006** (Belgium, Croatia, Estonia, France, Greece, Ireland, Latvia, Poland, Portugal, Romania, Slovakia and Spain—plus Norway (non-EU)). A majority (64%) of all countries reported that they have a national cancer plan in place and 55% have a national cancer registry, which meets the standards set by the European Network of Cancer Registries; 67% of these national cancer registries include information on screening. However, respondents indicated that cancer registries are very lacking with regard to the reporting of MBC (see also MBC section below).

A notable 79% of respondents said their country has national programmes/campaigns for primary prevention such as promoting a healthy lifestyle, fighting against obesity/smoking, but several of these countries reported that non-profit organizations are carrying out these activities rather than the government. Europa Donna's annual Breast Health Day campaign widely diffuses primary prevention and health information on the European level, thus aiding in this effort.

Fifty-six percent of countries reported that they have national, regional or local regulation dealing with genetic counselling to women and management of family history regarding genetic risks; in many cases there are requirements for this testing to be cost-free or low cost, at least in certain circumstances, such as strong family history of disease.

Moreover, a majority of respondents (64%) reported that their country has a regulation that deals with the provision of physiotherapy and lymphoedema treatment. Whether and to what extent this treatment is paid for by the national or regional healthcare or insurance is highly variable between countries; for example in Cyprus the cost is covered by NGOs and coalitions such as ED Cyprus rather than by public healthcare.

## 04

# MAMMOGRAPHY SCREENING AND DIAGNOSIS (QUESTIONS 20 – 30)

Seventy-four percent of countries polled have an organised population-based breast cancer screening programme set up in accordance with the “European Guidelines on Breast Cancer Screening and Diagnosis,” and 68% indicated that women between 50 and 69 in their country are invited to attend mammography screening every two years.

With regard to invitations to attend screening:

	YES	NO	DON'T KNOW	TOTAL
Are women invited to attend screening with a letter?	81.25% 26	18.75% 6	0.00% 0	32
Does the letter set a fixed appointment?	46.88% 15	50.00% 16	3.13% 1	32
Is there a follow up call to remind about the appointment?	25.81% 8	67.74% 21	6.45% 2	31
Has there been a digital evolution in the invitation/communication process the past 5 years?	34.38% 11	46.88% 15	18.75% 6	32

With regard to the outcome of the screening evaluation:

	YES	NO	DON'T KNOW	TOTAL
Is a woman whose screening came out negative informed by letter?	74.19% 23	22.58% 7	3.23% 1	31
Is a woman whose screening shows the need for additional examination informed by a letter plus a phone call?	64.52% 20	32.26% 10	3.23% 1	31
Is the medical/technical staff providing information services duly trained in communication skills to patients?	51.61% 16	35.48% 11	12.90% 4	31

Sixty-two percent of respondents reported that breast screening in their country is performed through state-of-the-art technology such as digital mammography or digital breast tomosynthesis (DBT), though **as pointed out by the advocate from Bulgaria, “The state care centres are not equally equipped. Private oncology hospitals have the most modern equipment. For example, as far as I know, 3D Mammography is performed only in a large private clinic in the capital city.”**

**In only 59% of countries that responded, in the case of high mammographic breast density in an otherwise asymptomatic woman additional tests are generally carried out through digital mammography or DBT.**

But in good news, 94% claimed that in their country all women diagnosed with breast cancer usually begin treatment within a reasonable time from the date when they receive their diagnosis. Furthermore, 79% said their country had a protocol dealing with diagnosis (invasive and non-invasive) in accordance with the European Guidelines and 68% said that their country uses biopsies for diagnosis through needle core rather than fine needle aspiration cytology, per the recommendation from the ECIBC Guidelines. And 71% responded that in their country clip-marking is used for surgical planning, as suggested by the ECIBC Guidelines.

## 05

# SPECIALIST BREAST UNITS (QUESTIONS 31 – 46)

Fifty-five percent of respondents indicated that their country has Specialist Breast Units (SBUs) but several stated either that they are not certified or, as one put it, “Far from all meet the EUSOMA standard.” Regarding distribution of SBUs, in many countries they are not well distributed in the territory and they do not cover the entire population:

	YES	NO	DON'T KNOW	TOTAL
Are they well distributed throughout the territory?	46.67% 14	53.33% 16	0.00% 0	30
Do they cover the whole population (i.e. a specialist breast unit for every 250,000 to 300,000 people)?	40.00% 12	53.33% 16	6.67% 2	30

Of these, 53% have a Unit large enough to enable a minimum of 150 newly diagnosed cases of breast cancer and treat at least 50 cases of MBC per year. In addition, **66% reported that SBUs in their country have multidisciplinary teams, though some do not have a data manager or a specially trained breast care nurse.**

Furthermore, between 64% and 70% indicated the following: patients receive practical advice, support and counseling from a specialist breast care nurse, a core team member with professional psychological training, or a psycho-oncologist; all members of the multidisciplinary team attend a weekly meeting to discuss diagnoses, pathological findings following surgery and to evaluate treatment options; and all treatment received by a person attending the SBU is under the supervision of the Unit, even if the treatment is not administered there (e.g., radiotherapy or cytotoxic treatments).

In response to the question, “As far as you know, do people who attend SBUs feel that they receive proper treatment?” 78% responded affirmatively and only 9% responded in the negative (13% didn't know). And 71% indicated that in their opinion the majority of SBUs in their country offer state-of-the-art equipment and technology and high levels of treatment.

Between 67 and 73% of respondents indicated that communication of each step of the treatment is effectively explained to the patient; there is a protocol dealing with post-diagnosis treatment options in line with the most recent International Guidelines published by ECIBC/JRC; and there are structures, programmes and services aimed at providing counselling, sustaining and advising breast cancer patients. Of these programmes providing counselling, 57% of countries have publicly funded services.

**However, only 34% indicated that there is a certification/accreditation system for SBUs in their country and 41% said that there is an authority in charge of monitoring the quality of SBUs in their country.**

Finally, for those whose country does not have SBUs, 72% said that they do have health facilities specialised in treating cancer.

## 06

# METASTATIC BREAST CANCER (QUESTION 47)

The table below illustrates the current picture of Metastatic Breast Cancer care in responding countries in Europe from the patient perspective:

	YES	NO	DON'T KNOW	TOTAL
Do women who have been diagnosed with MBC have access to services within a Specialist Breast Cancer Unit?	61.76% 21	35.29% 12	2.94% 1	34
Can women with MBC return to the health facilities where they were initially treated for on-going care, and follow-up including palliative care?	79.41% 27	17.65% 6	2.94% 1	34
Are there special health care units/departments to care for MBC?	8.82% 3	82.35% 28	8.82% 3	34
Is communication of each step of or change in therapy effectively explained, underlining positive and negative aspects of each option, so that women with MBC can make an informed decision?	67.65% 23	23.53% 8	8.82% 3	34
Are all drugs/therapies which have been proven to be effective available to women with MBC at no charge/paid by the Public Health system?	67.65% 23	29.41% 10	2.94% 1	34
Are there structures, programmes, facilities and services aimed at providing counselling, sustaining and advising women with MBC regarding employment, return to work, financial concerns, insurance coverage, family concerns, psychological issues, etc.?	52.94% 18	47.06% 16	0.00% 0	34
Are they publicly funded? Please explain in comments (below)	40.63% 13	50.00% 16	9.38% 3	32
Is there a Registry that records MBC cases?	25.00% 8	65.63% 21	9.38% 3	32

Although there are positives such as women with MBC in many countries being able to return to health facilities where they were originally treated, generally good communication with health care professionals in terms of decision-making regarding therapies available and a good drug/therapy availability, as one respondent commented, "There is a lot of work to be done for metastatic patients."

**Still today, 35% of European women living with MBC do not have access to SBUs.** Lacking are special health care units or departments to care for people who have MBC, there is a **lack of programmes and services providing counselling**, employment and return-to-work advice, addressing financial concerns, insurance coverage and family issues. Most glaring is the existence of **very few registries that record MBC cases.**

## 07

## MISCELLANEOUS, INCLUDING COVID-19/CANCER CARE (QUESTIONS 48 – 52)

In good news, 85% indicated that they have noticed changes in national legislation and/or health policies relating to cancer or breast cancer services in the last 10 years. Almost all cited positive developments: patients are treated with a personalised treatment plan, the role of patient organisations/advocates have become more important with time, (more) SBUs have been established, lower age for the onset of mammography screening or the implementation of screening programmes, increased clinical trials availability, patient empowerment, early breast cancer detection, greater patient reimbursement for molecular signatures tests, improvements in societal awareness, legal improvements, gradual modernisation of oncology hospitals, increased public spending and secured access to modern medicines for treatment.

However, **only 54% said that their country has passed legislation protecting or implementing breast cancer survivors' right to return to work; 42% of countries have passed legislation protecting or implementing survivors' right to access insurance; and only 12% of countries polled have passed "right to be forgotten" legislation for cancer survivors.**

Regarding **Covid-19**, 69% claimed their health system reacted to the emergency in view of providing cancer patients Covid-free pathways to screening and treatment. **Many indicated that screening was suspended and services and interventions were delayed as a result of the pandemic.** Further, problems occurred (such as in Ireland) in that **women with MBC were faced with attending more than one location for treatment due to safety protocols and found this difficult, access to treatment was often limited, queues for radiation and surgery were now much longer, and many patients shifted their priorities to Covid-19 and did not comply with their treatment plans.**

# 08 CONCLUSIONS

As pointed out by reporting countries, progress has been made in breast services in Europe over the past ten years. An increasing number of countries have a cancer plan, cancer registry for early breast cancer, campaigns for primary prevention, regulation in place for those with genetic risks, and regulation for physiotherapy and lymphoedema treatment. A relatively high number of countries have an organised population-based breast cancer screening programme, and 94% of respondents said that in their country all women diagnosed with breast cancer usually begin treatment within a reasonable time from the date they receive their diagnosis. Furthermore, countries are increasingly using state-of-the-art methods such as needle core aspiration for biopsies and clip-marking in surgical planning. Fifty-five percent of countries reported that they have SBUs, many of which use state-of-the-art equipment.

With regard to the treatment of people with MBC, in many countries patients are able to return to health facilities where they were originally treated, generally good communication with health care professionals exists in terms of decision-making regarding therapies available and there is by and large a good availability of drug/therapy.

**In spite of the progress made, numerous challenges still exist.** Not all countries' parliaments have agreed to implement the European Parliament Resolutions of 2003 and 2006; many countries still do not have a national cancer plan or cancer registry in place. A high percentage of countries do not have a committee/advisory board/group in their national parliament/government, such as a Ministry of Health, that deals with breast cancer. Genetic counselling, physiotherapy and lymphoedema treatment are not always available at no- or reduced-cost. Not all countries have cancer screening and when it is available European Guidelines are not always followed. Public breast cancer centres within a country are often not equally equipped, and certain procedures are only available in bigger cities. In many countries asymptomatic women with high breast density do not receive additional tests.

Although many countries have SBUs, a high number are not certified and do not meet the EUSOMA standard. In fact, in numerous countries no certification/accreditation system for SBUs exists and/or there is no authority in charge of monitoring the quality of SBUs. Moreover, in many countries SBUs are not well distributed in the territory and they do not cover the entire population. Although many SBUs have multidisciplinary teams, some lack certain personnel such as a data manager or a specially trained breast care nurse. Much still needs to be done in terms of SBUs and ensuring that they meet standards, thus illustrating the importance of the ECIBC completing its work.

For MBC, special health care units or departments to care for people who have MBC are lacking, and too few countries have programmes and services providing counselling, employment and return-to-work advice, addressing financial concerns, insurance coverage and family issues. Most grave is the existence of very few registries that record MBC cases; without adequate data it is impossible to evaluate effectively whether those with MBC receive adequate support.

Regarding survivorship, relatively few countries have passed legislation protecting the right to work, the right to access insurance and the right to be forgotten.

Such issues are only exacerbated by Covid-19 as money, resources, and public attention (including that of breast cancer patients) are diverted due to that health emergency. Provisions must be made to ensure that breast services can continue safely and effectively to avoid additional deaths stemming from a lack of diagnosis or inadequate treatment.

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