

DECEMBER 2020

EUROPA DONNA AND COVID



ADDRESSING THE
CHALLENGES OF BREAST
CANCER CARE
DURING THE COVID-19
PANDEMIC IN EUROPE

02 OVERVIEW:

At the beginning of 2020, the COVID-19 pandemic caught many people and their health care services off guard. Patient organisations including EUROPA DONNA – The European Breast Cancer Coalition and its national groups quickly reacted to the unfolding situation to support advocates and women across Europe to access breast services under difficult and ever changing circumstances. This report highlights the Coalition's work, and that of some of our close collaborators, in light of COVID-19 from March through December 2020 and what we have learned.

EUROPA DONNA DIGITAL ROUNDTABLES:

In April and May 2020, to provide support for EUROPA DONNA member organisations and evaluate the COVID-19 situation for breast care services in Europe, the ED Head Office held four separate roundtables via Zoom with ED National Representatives from **Albania, Armenia, Bulgaria, Cyprus, Czech Republic, Denmark, Finland, France, Georgia, Greece, Israel, Italy, Malta, the Netherlands, Romania, Spain, Serbia, Sweden, Switzerland and Turkey**. Many countries were in various degrees of lockdown, with oncological services delayed or reduced. COVID-free facilities or corridors were often not available, and accessing hospitals was either forbidden or advised against. Some cancer centres continued with surgery, radiotherapy and chemotherapy, but follow-up appointments were postponed or offered by telephone. Rehabilitation and lymphoedema therapy were offered by video in a few countries. In most places, the screening programme was suspended; in the countries where it was not, participation was reduced. The general feeling among ED national leaders was that such service interruption was temporary but with the possible resulting consequence of numerous later diagnoses of breast cancer that in some cases could equate to more developed and harder to treat tumours.

During this time, many of EUROPA DONNA's national organisations were busy providing information on breast cancer and COVID-19, primarily support services and counselling for women via telephone, video-conference or social media, as great numbers of women being treated were in isolation at home.



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PROBLEMS HIGHLIGHTED BY EUROPA DONNA NATIONAL GROUPS:

During the Coalition's meetings with its national organisations, many common issues arose. In numerous European countries, upon the COVID-19 outbreak the following occurred:

- It took time for health systems to organize COVID-free paths and to implement treatment guidelines with the aim of ensuring safe access to treatment and management of care
- Many cancer treatment plans were changed so that people would not have to spend as much time in these facilities as they usually would
- Screening was suspended, and treatment was prioritized according to urgency
- Medical appointments were spread out in order to avoid contact between people
- Universal masking for patients and hospital staff became the norm as did testing for COVID-19 before surgery or chemotherapy
- Shorter hospital stays were enacted to limit exposure, time and effort by health providers
- Use of telemedicine increased

Resulting problems were:

- A reduction of health structure capacity
- The suspension of screening and elective care which caused an immediate fall in diagnosis, with the obvious consequence of later diagnoses of more advanced breast cancer
- In some cases, breast cancer surgery was performed but not reconstruction (considered elective care)
- Hospital stays were as short as possible with no access to caregivers and family, so the patients felt abandoned and alone - "left like a parcel"

Advocates observed that telemedicine is a good solution in lieu of in-person appointments given the circumstances, but it is not always effective. Many doctors and patients are not used to telemedicine and it takes time to adapt. This can exacerbate patients' feelings of anxiety and fear of not receiving the timely and effective treatment one needs.

ED national organisations reported fear and anxiety of most breast cancer patients and survivors. In particular:

- Health structures were perceived by patients as unavailable or unsafe, as they were shifting priorities
- Patients were afraid and felt unsafe. There was a great deal of confusion and they did not feel effectively protected either by the authorities or by the health institutions which appeared to be struggling against being inundated beyond their capacity

This resulted in:

1. General anxiety and fear felt by breast cancer patients and survivors, and fear of contracting the virus while undergoing treatment
2. Fear of the consequences of delays in treatment or care
3. Fear of not being a priority in the health system
4. All of the above were compounded by loneliness and isolation brought about in a lockdown situation

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ACTIONS TAKEN BY EUROPA DONNA NATIONAL GROUPS:

EUROPA DONNA's National Representatives shared how their organisations were coping and trying to help breast cancer patients and survivors in their own countries during the pandemic. They all noticed a tendency of breast cancer patients and survivors to isolate themselves, not only physically, but also more so than lockdown or travelling restrictions required.

To combat this tendency toward isolation and to provide assistance where needed, advocates from EUROPA DONNA national organisations carried out the following programmes:

- Calling patients at home; they kept women connected virtually with online events, webinars, meetings, cooking and yoga courses
- Running hotlines and trying to provide fast and reliable information on guidelines and procedures
- Assisting people by making masks
- Organising and offering private transport to health facilities
- Giving support for shopping, getting supplies
- Delivering food and care packages

The evolving situation:

Two additional roundtables were held in early December 2020 to follow-up on the evolving situation with National Representatives from **Albania, Armenia, Belgium, Cyprus, Finland, France, Italy, Luxembourg, Malta, the Netherlands, Romania, Serbia, Spain, Sweden, Turkey, the UK, and Ukraine**. In most countries, the second wave of COVID-19 has not impacted the screening programme as it did in the spring, however women are still afraid to attend due to safety concerns. They are generally anxious, fearing that if treatment or surgery is needed they will have to face it alone. Many are postponing medical appointments and procedures to spring 2021 when "maybe there will be a vaccine." EUROPA DONNA national groups are working diligently to communicate to the public that it is safe to attend screening and that women should not put it off. Another topic that was prevalent in most countries is the severe adverse psychological effect the pandemic is having on patients, and ED groups are running online programmes to combat this. Overall, representatives of patient groups reported that they have been able to continue modified programmes virtually in spite of the challenges they face.

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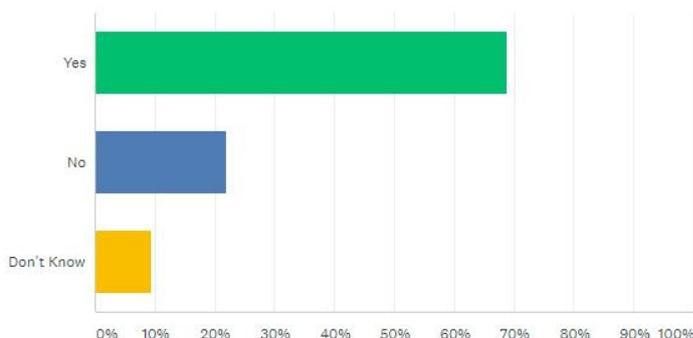
THE 2020 EUROPA DONNA SURVEY:

During the summer of 2020, EUROPA DONNA undertook a survey project to provide a snapshot of the current state of breast services in Europe from the perspective of patient advocacy organisations, including their experiences as advocates regarding COVID-19 and breast cancer. We received one response per country from breast cancer advocacy leaders representing EUROPA DONNA national groups in 34 countries.

Regarding COVID-19, 69% of respondents claimed their health system reacted to the emergency in view of providing cancer patients COVID-free pathways to screening and treatment. Many indicated issues, for example that screening was suspended and services and interventions were delayed as a result of the pandemic. Further, problems occurred in that in some cases 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 were not complying with their cancer treatment plans. Almost 22% of respondents indicated that their health system did not provide cancer patients with COVID-free pathways to screening and treatment. One reported: “national policy to deal with COVID-19 was not in line with cancer patients and other chronic diseases. The measures were categorical, poorly communicated, and fear prevailed over reason.”

Has your health system reacted to the COVID-19 emergency in view of providing cancer patients COVID-free pathways to screening and treatment?

Answered: 32 Skipped: 2



ANSWER CHOICES	RESPONSES	
Yes	68.75%	22
No	21.88%	7
Don't Know	9.38%	3
TOTAL		32



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PRESENTATION ON TBCT PAPER AND CONTRIBUTING TO THE EU RESPONSE TO THE PANDEMIC:

In the late spring, our External Affairs Director Marzia Zambon participated in a webinar on cancer care in times of COVID-19 organised by ED Georgia. She spoke about the Coalition's role in the *Transforming Breast Cancer Together* (TBCT) initiative, which was established when influential policy makers and organizations strongly committed to breast cancer, including EUROPA DONNA, began to collaborate in 2017. The group's mandate is to elevate breast cancer as a Health Policy Priority. In April 2020, the TBCT group published the paper, "Impact of COVID-19 on Breast Cancer Patients." This set out seven key challenges in accessing appropriate treatment and care during the pandemic:

1. Diminished resources to care for breast cancer patients
2. Delays in screening and diagnosis
3. Delays in breast cancer treatment
4. The discontinuation of clinical trials
5. Emotional distress caused by uncertainty of treatment and follow-up
6. Emotional distress caused by COVID-19 fear
7. Emotional distress for cancer survivors

It called on authorities, both at the EU and national levels, to take the necessary measures to tackle the above issues and to ensure the minimum level possible of disruption to the treatment and lives of all patients suffering from difficult conditions, such as breast cancer.

See →

https://www.europadonna.org/wpcontent/uploads/TBCT_COVID19_Statement.pdf

Marzia then outlined the support that EUROPA DONNA offered its member organisations via digital roundtable sessions, providing COVID-19-related information from reliable sources, encouraging the following of national guidelines, and trying to ensure that its 2020 programme was minimally affected.

She noted that the Coalition has also been following and contributing to the EU Commission's Response to the pandemic: this response has involved providing emergency support, a joint procurement agreement for medical equipment, ensuring high-quality virus testing, creating a European team of coronavirus experts, providing data and support through the European Centre for Prevention and Disease Control, and publishing updated information and guidelines.

See →

https://ec.europa.eu/info/live-work-travel-eu/health/coronavirus-response/public-health_en

07

EBCC 12 - OCTOBER 2020:

EUROPA DONNA is co-organiser of this conference together with European Society of Breast Cancer Specialists ([EUSOMA](#)) and the European Organisation for Research and Treatment of Cancer ([EORTC](#)). At the 12th European Breast Cancer Conference ([EBCC-12](#)), which was held virtually for the first time in early October 2020, COVID-19 and its impact on breast cancer was of course one of the central topics. Following are some of the main findings discussed during the conference regarding COVID-19 and treating breast cancer:

- In a study in the Netherlands, suspension of screening programmes from March to June 2020 was associated with a decrease in the number of women diagnosed with breast cancer
- Another model-based study of the Dutch breast cancer screening programme found that increasing capacity to achieve a full catch-up predicted better outcomes than delaying screening
- A third study in the Netherlands showed that, among women with breast cancer during the pandemic, 48% felt lonely and 27% were worried about the effect on their aftercare
- An algorithm has been developed to identify post-menopausal women with early luminal breast cancer in whom neoadjuvant endocrine therapy can be used in order to delay surgery, after a full risk-benefit analysis
- Telemedicine consultation should be used whenever feasible, multidisciplinary team working needs to be maintained, delays in surgical treatment should be reduced and based on evidence

This is a difficult and challenging period for all citizens and certainly for breast cancer patients and survivors as they may be at higher risk for contracting COVID-19 in a more serious form. EUROPA DONNA encourages everyone first and foremost to follow the guidelines and requirements in force in their individual countries. In addition, various guidelines on COVID-19 and breast cancer have been released from organisations that rely on up-to-date, accurate, evidence-based information:

The **European Commission Initiative on Breast Cancer (ECIBC)** has an information corner on COVID-19 and breast cancer providing information and guidelines on the management of breast cancer screening and care during the COVID-19 pandemic.

See →

<https://healthcare-quality.jrc.ec.europa.eu/covid-19-information-corner>

The **European Medicines Agency (EMA)** has published reliable information to patients and healthcare professionals.

See →

<https://www.ema.europa.eu/en/human-regulatory/overview/public-health-threats/coronavirus-disease-covid-19>

The **European Society of Medical Oncology (ESMO)** has published guidance for clinicians and has defined clinical situations that are high, medium and low priority for key settings: outpatient visits, diagnosis and imaging (e.g. population screening is considered low priority), surgery, radiation, and medical treatment.

See →

<https://www.esmo.org/guidelines/cancer-patient-management-during-the-covid-19-pandemic/breast-cancer-in-the-covid-19-era>

Ecancer has published a “COVID-19 and cancer: Useful resources” section on its website with open access articles, expert videos and blogs, and the latest news on COVID-19. It also has a “Guide for Patients” which gives a wide array of guidance on COVID-19 for people with cancer, for people who have recovered from cancer and for those supporting those with cancer.

See →

<https://ecancer.org/en/news/17527-covid-19-resources>

The **ABC Global Alliance** has published a resource page on COVID-19 and cancer/MBC.

See →

<https://www.abcglobalalliance.org/news-and-useful-resources/coronavirus-2019-and-cancer/>

Furthermore, on 4 August, the ABC Global Alliance (of which EUROPA DONNA is a member) together with 8 other global cancer coalitions and alliances, representing 650 patient advocacy and other cancer organizations and the interests of over 14 million patients around the world, released a statement to call for a global plan of action for cancer to meet the challenges of future pandemics or health crises. The statement highlights the need for patient advocacy organizations, governments and health services at the national and global level to work together with other key stakeholders including industry and academia, to ensure that we regain the ground that has been lost to the COVID-19 pandemic.

See →

<https://www.abcglobalalliance.org/wp-content/uploads/2020/08/COVID19-Alliance-Statement-August4.pdf>

09

IN CONCLUSION: COVID-19 AND OPPORTUNITIES FOR BETTER BREAST CARE SERVICES

The advent of COVID-19 has brought about a new normal in just about every aspect of being, including the experience of breast healthcare. Telemedicine and e-healthcare are no longer little-used novelties but instead have now often become go-to tools of the pandemic; it is time for health systems, doctors and patients to adapt to this technology and learn to bring healthcare into the home rather than continuing its hospital-centric course. Moreover, the pandemic has brought about treatment that is less invasive and less toxic while remaining effective: radiotherapy sessions with decreased intensity, oral chemotherapy treatment and online follow-up make both the patient's life and the doctor's job easier. Follow-up visits not involving physical examination can occur as a teleconference rather than an in person visit that would entail transport and access to healthcare facilities with possible exposure to COVID-19.

During these months in which we have all lived with the frustrations and heartbreaks of COVID-19, European institutions, patient and health organisations, and advocates have faced challenges like never before. Industry has put massive amounts of resources in a race to find effective vaccines and national and international authorities have greatly accelerated testing and approval procedures. All have proven to be not only resilient in the face of the biggest health emergency in a century but have also joined forces seeking common policies and implementing guidelines in an attempt to best serve everyone in the face of COVID-19, including people with breast cancer. As it proved possible to come together in the face of COVID-19 it will be easier to once again align over other health issues, such as a joint investment in cancer research, data harmonization and digital evolution, common policies aimed at the implementation of guidelines in member states, telemedicine, remote and home services.



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