



EUROPA DONNA 2022

Survey on COVID-19 and
the State of Breast Services in Europe





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September 2022

During the spring of 2022, EUROPA DONNA – The European Breast Cancer Coalition undertook a survey project to provide a snapshot of the current state of breast services in Europe from the perspective of patient advocacy organisations, with respect to their experiences as advocates regarding COVID-19 and breast cancer. This project follows a survey carried out in September 2020 covering the state of breast services in Europe which had a section dedicated to COVID. The goal was to gain a better understanding of how the breast cancer landscape has changed and where European countries stand now, following what for many countries has been more than two years of disruption and instability as consequences of the pandemic.

Seventeen questions were posed, on the topics of COVID-19 and:

- **BREAST CANCER SCREENING**
- **DIAGNOSIS, TREATMENT AND FOLLOW-UP**
- **CLINICAL TRIALS**
- **BREAST CANCER ADVOCACY**
- **POLICY, LEGISLATION AND TELEMEDICINE**

RESULTS

Context and diagnosis

Two years ago, during the summer of 2020 and the height of the pandemic, Europa Donna conducted a survey to get a snapshot of the state of breast services in Europe from the perspective of patient advocacy organisations, which included questions on whether and how countries' health systems were reacting to the COVID emergency. We received responses from 34 countries, 69% of which claimed their health system was providing cancer patients with COVID-free pathways to screening and treatment. Many indicated that screening was suspended and services and interventions were delayed. Further, problems occurred 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 therapy and surgery were now much longer, and many patients shifted their priorities to COVID-19 and did not comply with their treatment plans.

The current survey was conceived to get an understanding of how that situation has changed. It was conducted from April through July 2022 and we received one response per country from Europa Donna organisations in the following 29 countries (17 of which are European Union members): Albania, Armenia, Austria, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Greece, Israel, Lithuania, Malta, Monaco, the Netherlands, North Macedonia, Norway, Portugal, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, Turkey, and the UK. The respondents were all current Europa Donna National Representatives or National Delegates or other long-time leaders of their organisations with deep knowledge of advocacy in their country.

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

BREAST CANCER SCREENING

In 69% of European countries reporting, the wait time for having a mammogram has by and large been said to have gone back to normal following suspension and delays related to COVID-19. According to 10% of respondents, it was never delayed in the first place. But 21% of the reporting countries (Denmark, the Netherlands, North Macedonia, Russia, Slovenia, the UK) are still reporting delays in this essential service.

Likewise, women are generally returning to the screening programme: 76% of respondents stated that women are participating at pre-COVID levels. However, advocates from countries including Cyprus, the Netherlands, North Macedonia, and Serbia are reporting continuing reduced attendance. To encourage women to attend screening, a slight majority of Europa Donna groups, 52%, began running communication campaigns on the topic of “it is safe to attend screening” once the programme started again.

DIAGNOSIS, TREATMENT AND FOLLOW-UP

Twenty-four percent of respondents reported that some women still fear going for check-ups and treatment in their countries, but most stated that the vast majority of women now attend medical appointments without hesitation. Almost all countries, 86%, claimed that breast reconstruction procedures are once again being offered or that they were never delayed during COVID-19. Some countries still face delays, though; Slovenia and the Netherlands, for example, reported that the waiting time for secondary reconstruction is now two years or more.

Advocates are reporting the following breast cancer treatment delivery and follow-up changes after COVID-19 (listed here starting from the highest number of mentions):

- Many stated that healthcare professionals have started using telemedicine and email communication much more frequently, especially for follow-up visits.
- Some noted that screening programmes and services from breast cancer treatment delivery to follow-up continue to be delayed. Patients in several countries are now struggling to continue with new, innovative therapies.
- Hospitals in several countries lack some medicines for cancer patients, including breast cancer.
- One respondent claimed that many of the available healthcare funds in her country continue to go to COVID-19 and this has led to a decrease in diagnosis and treatments.
- One respondent stated that there is more neo-adjuvant treatment provided now. A number of hospitals changed their policy and now women with suspected breast cancer go immediately to radiology instead of to the breast services department.

- In one country during the pandemic some oncology centres initiated a Virtual Multidisciplinary Board, which allows direct communications between health experts from tertiary health centres to discuss individual patients' therapy.

Worryingly, 69% of respondents reported that they have information that, since the start of the COVID-19 pandemic, breast cancer diagnosis has decreased in their country. Countries providing statistics included the following:

- Slovenia claimed that in 2020 approximately 15% fewer women were diagnosed with breast cancer and in 2021 about 10% fewer received a diagnosis.
- In Monaco, there has been a 25% decrease in breast cancer diagnoses.
- The number of detected cases decreased by 25 – 30% in Russia due to limited access to screening.
- In Finland, there have been 6% fewer breast cancer diagnoses than expected.

A number of respondents claimed that no statistics are publicly available on this information in their countries, but that it is widely suspected among health professionals and advocates that breast cancer diagnoses have decreased since the start of the pandemic.

Only 21% said they had information on the change in metastatic breast cancer diagnoses since the pandemic began in early 2020; several respondents stated that it is too early to understand the ramifications of COVID on the number of increased MBC diagnoses.

CLINICAL TRIALS

Thirty-one percent of reporting countries' advocates claimed that access to clinical trials was limited during the early days of the pandemic, but 28% of countries did not report limited access and 41% of respondents did not know their status. The respondent from Slovenia said that access was limited in her country because doctors did not have time to introduce and include patients in new trials during the pandemic, but ongoing trials continued. In the UK there was reportedly less access to trial nurses, less presence of professionals running trials in clinics, treatments were slightly altered (more use of endocrine therapy in neoadjuvant setting if appropriate), and chemotherapy was stopped in the first COVID wave, so there was no access to chemotherapy trials, and there were no surgical trials running since there was no guarantee of surgery theatre space.

BREAST CANCER ADVOCACY

Forty-five percent of responding advocates claimed that their role has changed since the beginning of the pandemic and 76% of their organisations have changed the way they work: the great majority reported that they have now moved a great deal of their work online or by telephone, and many stated that their workload generally has increased. Some advocates continue to work from home and perform their psychosocial support activities and other heretofore in-person activities online. Whether or not the advocates are working from home, by and large communications, activities, advice and private talks with patients are now held online.

One respondent remarked, **“We no longer do lunches, tea, coffee. We limit the number of people in the association. There isn’t the same conviviality [as there was before], and we are sorry.”** ED Netherlands is now focusing on screening and self-assessment, advocating for patients not to delay procedures and for hospitals to allow patients to bring a partner or friend to appointments. It was reported by several respondents that patient groups’ lack of face-to-face contact “has led to a lot of extra emotional suffering” amongst the women with breast cancer who use their services. The responding advocate from Malta stated: **“The duties have become more frustrating, especially online meetings, the fact that one cannot plan, the need to protect patients and committee members.”**

ED Denmark has shifted its focus towards political issues. In Russia, advocates had to redouble their efforts to meet the need for patient care in the absence of access to medical care during the pandemic. ED Sweden took on a larger role by spreading information on vaccine availability and fielding calls from anxious young women who would in normal times contact local breast cancer groups. Fifty-nine percent of organisations reported that they have experienced difficulties with fundraising for their activities since the pandemic began. The respondent from Israel, for example, stated: **“Our main fundraising campaign is the door-knock campaign: school children from all over the country literally knock on the door, requesting donations. This obviously could not be done during the pandemic.”** However, a number of advocates stated that their organisations were able to withstand the funding losses as they were also spending significantly less money on conferences and in-person events during the lockdowns and COVID-related closures and were therefore spending less money on their programmes. For 38% of reporting organisations, fundraising has gone back to pre-COVID levels.

Some respondents (Albania, Netherlands, Spain) have cited the Ukraine-Russia war as causing additional problems with fundraising, as **potential donors are “concerned about other things”**. In addition, the respondent from ED Russia reported that fundraising has fallen by 90% due to the war. Respondents from Tajikistan and Russia stated that the war was adversely affecting patient treatment. Due to the situation, prices for chemotherapy drugs have become more expensive in Tajikistan as the drugs are usually bought by the patients themselves in pharmacies in Russia. As a result, ED Tajikistan has strengthened its efforts to provide drugs and chemotherapy to patients. In Russia, patient access to clinical trials has been completely suspended. (It should be noted here that Europa Donna did not receive a survey response from ED Ukraine, but we have been in contact with the forum’s leader who has informed us that unfortunately all functions of the organisation have been temporarily suspended due to the war.)

POLICY, LEGISLATION AND TELEMEDICINE

The majority of respondents, 66%, claim they have not changed the way they interact with their health ministry and policymakers since the start of the pandemic. Slovenia has been able to interact more, while several other countries (Netherlands, Russia, UK) have had less contact, citing that other themes such as COVID have been more urgent and thus less time has been allocated for breast cancer advocacy issues. In Denmark, advocates are taking on more initiatives, like arranging debates on screening, diagnosis and initial treatment as well as treatment for MBC at an important national meeting. ED Russia reported that access to policymakers was severely restricted and only online.

However, 59% of countries have reportedly modified legislation regarding working from home (which especially benefits people who are at-risk for COVID complications such as breast cancer patients). Some respondents commented that although legislation hasn't changed in their countries, working from home is now more encouraged by government and by many employers. Several have stated that numerous people in their countries were working at home during the height of the pandemic; some are now back in the office, but many are working hybrid.

Thirty-one percent of countries have allegedly modified legislation regarding telemedicine, making it easier for patients to access medical care. In Slovenia it is now covered by insurance. Moreover, 41% of reporting countries' hospital health facilities are said to have implemented telemedicine. In the UK many appointments were carried out by telephone or video during the height of the pandemic, and they still are for follow-up. A plastic surgery seminar that explains reconstructions to patients has become a webinar once restarted, with the unfortunate consequence of patients missing out on potential peer support. In a few countries, telemedicine is only used between medical professionals. The respondent from Finland noted: **“Phone calls now replace appointments; not everyone is happy with this. Video-calls are not so common yet, but patients like these better than receiving a regular phone call. Digital care paths or apps for patients are in use in some hospitals.”**

CONCLUSIONS

Breast cancer services in Europe are recovering following more than two years of the COVID-19 pandemic. According to the results of this survey:

- Women's wait time for having a mammogram has by and large gone back to normal following suspension and delays related to COVID-19.
- Breast reconstruction is once again being offered or it was never suspended at all in most countries.
- Women are mostly returning to screening, treatment and follow-up programmes without fear.

However, some issues brought about by COVID are reportedly proving difficult to solve in various countries:

- Wait times for breast services are sometimes significantly longer than they were prior to the emergence of COVID.
- Some hospitals lack breast cancer drugs as a result of the pandemic.
- In at least one country available healthcare funds have been diverted to COVID support, to the detriment of breast cancer care.

Of greatest concern is that **many responding advocates have statistics that breast cancer diagnosis has decreased significantly in their countries since the start of the COVID-19 pandemic.** While a number of respondents noted that few statistics are publicly available on this information in their countries, the majority of these went on to state that it is widely suspected among health professionals and advocates that breast cancer diagnoses have decreased since the start of the pandemic. This shows that fears are likely coming to pass that one result of the pandemic will be a greater percentage of breast cancers that will be detected at a later stage, when they are more difficult to treat. As responding advocates noted, it is probably too early to understand what the ramifications will be for additional MBC diagnoses.

On a positive note, breast cancer advocacy organisations, health systems and governments have adapted to the pandemic to the benefit of the women in their countries. Many respondents stated that their **governments have enacted legislation on telemedicine, and healthcare professionals are now using telemedicine and email communication with patients much more frequently.** Patient advocacy organisations quickly moved their services online when the pandemic hit and many ran communication campaigns on the topic of “it is safe to attend screening” once the programme started again. **Numerous countries have modified legislation about working from home,** and in those countries without such legislation, working from home is now generally more encouraged by government and by employers.

Unfortunately, the adaptations that were made to avoid COVID infections in people who can be at high risk to adverse outcomes come at a price. Meeting online with healthcare professionals, support groups and advocates cannot replicate the in-person experience. **The psychological implications of missed opportunities for positive interactions should not be undervalued.**

Finally, although it ostensibly has nothing to do with COVID-19 or the survey conducted by Europa Donna, it should be noted here that several respondents brought up the issue of the Ukraine-Russia war and its negative ramifications for breast cancer care and advocacy. This is a conflict that has made an already challenging pandemic situation even more difficult for numerous countries.



EUROPA DONNA – The European Breast Cancer Coalition is an independent, non-profit organisation whose members are affiliated groups from countries throughout Europe. The Coalition works to raise awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optional treatment and care and increased funding for research. EUROPA DONNA represents the interests of European women regarding breast cancer to local and national authorities as well as to institutions of the European Union.



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