Metastatic BREAST CANCER

Europa Donna
2021 Survey Report

Metastatic Breast Cancer Quality of Care and Quality of Life from the Patient's Perspective in Europe

EUROPA DONNA
The European Breast Cancer Coalition

Overview

To kick off a new advocacy initiative for quality of care and quality of life improvement in patients with **Metastatic Breast Cancer (MBC)**, EUROPA DONNA – The European Breast Cancer Coalition (ED) conducted a survey of its member countries starting in September 2021 to learn about the patient's perspective on the current state of progress and areas that need improvement for people living with MBC in Europe. The purpose is to gather up-to-date information throughout European countries as part of a multi-phase ED project to drive change through the creation of a European-wide campaign to raise awareness of MBC and to promote optimal follow-up, rehabilitation, aftercare, survivorship and quality of life issues for and with women who have this disease.

Thirty-two questions were posed, on the topics of:

Treatment and Services for People with MBC:

- MBC diagnosis and genomic tests
- Clinical trials
- Psycho-oncology services
- Availability of support for family and carers

Legislation Protecting People with MBC:

- Discrimination in the workplace
- Other types of discrimination (insurance, right to be forgotten/remembered, social/ economic support)

Advocacy for People with MBC:

- Patient organisations
- Public awareness of MBC and stigma
- Next steps for MBC advocacy

Results

Context and diagnosis

The survey was conducted from September through December 2021 and we received one response per country from MBC leaders in Europa Donna national groups in the following 30 countries (20 of which are European Union countries): Albania, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Greece, Iceland, Israel, Italy, Lithuania, Luxembourg, Malta, the Netherlands, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, Turkey, Ukraine and Uzbekistan. Respondents were people in national Europa Donna organisations nominated by the National Representative who specialise in MBC advocacy; 33% of those who completed the survey reported that they themselves have MBC. Of the other respondents, all are currently Europa Donna National Representatives or National Delegates or other long-time leaders of their organisations with deep knowledge of advocacy in the country.

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

Treatment and Services
People with MBC

According to 25 out of 30 survey respondents (83%), the majority of the latest treatments and drugs are available in their country. The majority of the latest of those who indicated that they have the latest treatments, several qualified their response, saying that the latest treatments and drugs do not immediately become available or that reimbursement takes time or patients need to cover costs. In answer to the follow-up question, 82% indicated that their public health system pays for the treatment; 4% pay through private health insurance and 14% of MBC patients must pay for treatment with their own funds.

Describing a win for MBC advocacy, the respondent from ED Georgia noted, “I have HER2-positive ER-positive MBC; I'm thankful for Europa Donna Georgia`s project *Target for Life*, because now we have a co-financing program for Herceptin.” Likewise, the respondent from Europa Donna Serbia noted her forum's advocacy initiative, “Together with another patients' association, Europa Donna Serbia is involved in the campaign *Life is Worth*, aiming to introduce innovative therapies in the treatment of steroid receptor positive, HER2-negative MBC. CDK inhibitors are still missing on the list of approved drugs of national health insurance.”

Countries indicating that the latest treatments and drugs are not available are: Denmark, where Enhertu (TDXd) is not available for HER2-positive MBC; Uzbekistan; Tajikistan, where “access is limited both economically and geographically for women with MBC”; and Romania.

Two-thirds of people responded that tests for genetic mutations such as BRCA are available to all people in their country. Many qualified their response, stating that testing is available only in certain cases. For example, in Finland everyone under 40 years of age who has breast cancer or under 60 with triple negative breast cancer is eligible. In the Czech Republic the oncologists decide whether to ask for the tests. In Belgium the tests are only for people who have several relatives who have been diagnosed with breast cancer. In Georgia, however, the tests are deemed too expensive for the healthcare system, and in Ukraine people can only get tested using their own funds and going to private labs. Seventy-six percent responded that the national health system pays for the tests for genetic mutations, 16% pay out-of-pocket and 4% through private health insurance.

It seems that far fewer countries offer genomic tests to all people such as for PI3K if ER-positive at MBC diagnosis, with only one-third of respondents claiming their countries offer these types of tests. Many respondents qualified their response, stating that it is available for some categories of patients, or on request, or when indicated. Of the countries that offer the test, 69% of national health systems cover the expense. The respondent from Europa Donna Netherlands stated, “Some doctors propose it themselves, but often patients have to ask for it. There is still a lot of unfamiliarity.” This unfamiliarity seems to be widespread, as 30% of people responding to the question said they don't know if these types of tests are available to all people in their country at MBC diagnosis. More education in the MBC advocacy community needs to take place on this topic.

Fifty-three percent claimed that clinical trials are widely accessible in their country for people with MBC, not a particularly high percentage. Most of these people learn about clinical trials through their doctors (93%), followed by from patient groups and from the Internet/social media (tied at 27%). Several commented that usually patients who live close to the centres conducting the clinical trials are enrolled in clinical studies, and that those from small countries have to travel to other countries to participate. Thus, access to clinical trials remains unequal, due in no small part to where a person lives.

Psycho-oncology services are described as available in all but 10% of responding countries: in 43% of the countries, services are free and widely available; in 7% services are available but must be paid for; in 53% of the countries polled the services are limited.

When asked: "In general, do you feel treatment and services for people with MBC in your country are adequate today?", 53% responded no, 40% responded yes and 7% said they don't know. Those who responded no were asked as a follow-up, **"What do you think can be done to improve treatment and services for people with MBC in your country?".**

Responses were:

There is a need to have new treatments reimbursed.

Services can always improve and there is a need for more supporting services like physiotherapy and social/ psychological support. In some regions the services are fine but in other places services need to improve. Also services and care would benefit from being organised differently. As a patient you access different services and care at separate places or providers which isn't in the best interest of the patient! As a patient I often feel like I'm the one coordinating my treatment, care and support.

Europa Donna Georgia is the only group in Georgia, which has psycho-oncology services for MBC patients. We have agreement with IDC Psychologists group for free psycho-oncology services.

More facilities for rehabilitation, reimbursement for expenses due to limitations from the disease, psycho-oncologic support at a more organized level by the National Health System.

There is more to be done. First and foremost, navigation nurses are required, hopefully we will be getting one within the next 6 months or so. Additionally, patients need to be aware that they have MBC. Patients need to be educated so that they can become experts of their own disease. Knowing your own disease makes a person assertive and you can make decisions on treatment with your carers.

To introduce in the country the latest generation drugs and appropriate testing protocols, to make studies.

Rehabilitation or lack of that and many things you have to pay for.

Especially for psycho-oncology - we have only one department for the whole country... that is not enough. That is why ED offers psycho-social support.

New innovative therapies must be available for MBC. Besides, clinical studies and access programs must be conducted to a greater extent.

To improve communication and informing the patients about all the possible treatments and allow them to have better basis for decision-making.

Breast cancer groups and activities are mainly focused on early breast cancer, the 'survivors'. Many initiatives for 'after' cancer - which is extremely demotivating for MBC patients. It's also difficult to reach MBC patients.

Psycho-oncology should be prioritized. EMA approved products should be available.

Better care path. Not a fixed point of contact. Access to multi-disciplinary team.

Provision of the medications by state clinics, creation of the support for free.

Adequate government budget financing of the oncology systems in our country.

Everyone should have equal access to health services. For example, psycho-oncologist, dietician, dermatologist.

Finally, a strong two-thirds majority indicated that they feel partners, carers, children and family members of people with MBC *are not supported* in their country. Respondents from Israel, the Czech Republic, Slovenia, Belgium and Tajikistan noted, however, that local and national patient groups like Europa Donna provide services to support carers and family members, although not necessarily specifically for relatives of patients with MBC. **Also noteworthy, two respondents commented that people aren't always even aware that they have been diagnosed with MBC (probably either due to poor doctor/patient communication or because they do not want to accept their diagnosis) so they do not avail themselves of the resources available.**

Legislation Protecting
People with MBC

Almost half (47%) reported that laws exist in their country that protect people from discrimination in the workplace so that they can return to work between treatments or during treatment for MBC, but the laws differ from country to country. For example, the respondent from Europa Donna Denmark stated, “Employees have rights, however after a specific period of sick leave, the employer can dismiss the employee”. However, in Finland it is not legal to terminate the employment if the reason is illness. Many pointed out that these laws are general for cancer or breast cancer patients, and not specifically for people with MBC. Some also stated that in spite of existing legislation, discrimination continues to occur in the private sector, and others claimed that a flexible return to work depends on how much the employer is willing to adjust the job requirements to the patient’s particular situation. The respondent from Belgium recounted of her country: “There is support for cancer patients to go back to work or find a new job. But to get a contract usually you need to go to the company doctor to be approved. From my own experience I know that is an impossible hurdle for company doctors: if you have MBC the doctor cannot state you are fit for the job.” Europa Donna Georgia is currently working with lawyers to create and promote legislation that provides protections for patients with MBC.

> **Only 30% reported that their country has legislation that protects people with MBC from discrimination outside the workplace, such as insurance, right to be forgotten/remembered, social/economic support; 43% said that no such legislation exists in their country and, significantly, 27% did not know. This issue could be a point for education in the MBC advocacy community if such a high percentage of advocates are not even aware of the legislation in their country that could potentially protect this vulnerable group.**

Legislative protections that do exist vary greatly from country to country. The problem noted the most frequently by far was with insurance protection. Comments included:

Legislation is not specific to MBC. Once one gets cancer, insurance is unavailable. The right to be forgotten is included in the General Data Protection Regulation. As for social and economic support, it is a general law that is available for all sicknesses. However, recently the Maltese government began providing the collateral when a loan is required for the purchase of property following a cancer diagnosis.

There is economic support from the government, after examinations from government-appointed doctors. If the patient does not have support from her work, or s/he does not receive a pension. As for insurance companies, they do not insure cancer patients.

In Israel, there is a law protecting different types of discrimination against BRCA carriers.

Laws exist but are very difficult to make use of, and they do not cover the needs of patients.

We do not have any legislation regarding insurance (you do not lose it after diagnosis, but you cannot make a new life insurance after diagnosis), and we do not have a law for the right to be forgotten.
We have a good social support system in which people with MBC get at least a minimum pension.

There is legislation, but it is not sufficient. Insurance is a problem.

Private insurance discriminations exist even at the level of early breast cancer.

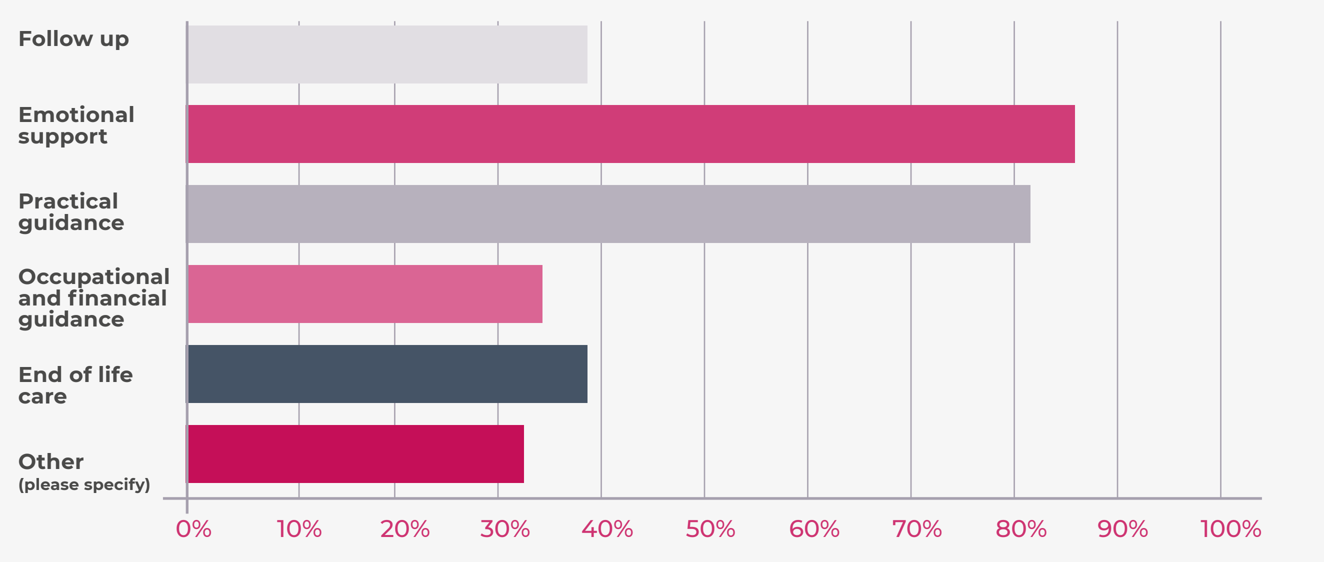
Certain sickness benefits can be accessed.

A general law exists that gives economic support to people who are under treatment either with sick leave or with an invalid pension. There is no specific protection against insurance discrimination nor right to be forgotten.

There is no legislation concerning insurance or the right to be forgotten
but there are sickness benefits and disability pension, and support for rehabilitation.

Advocacy for **People with MBC**

Ninety-three percent said that patient organisations in their country provide people with information on MBC. They indicated that patient organisations provide the following types of information:



Other activities mentioned:

Information and activities

Support groups, online access to oncologist and other professionals that answer questions

Advocacy, 13 October (MBC awareness day)

End of life care is barely mentioned in my country and not even palliative care; some patients do not realise they have MBC

Physiotherapy for lymphedema and all the above for free

Education about their illness is currently missing - it is a very sensitive issue how to explain to MBC patients about course of their disease, what can they expect and to support them at the same time

Medical information

Telephone consultations

Almost three-quarters (73%) indicated that people with MBC participate actively in their local breast cancer support or advocacy group activities/meetings, but only 43% have a group specifically for people with MBC. Of this fact, one person commented, “Two of us advocate fiercely for MBC but more collaboration is required on the matter. Many still think of awareness and of telling your story but MBC is beyond that... it is a chronic disease which is not easily lived especially when on chemotherapy.” Another pointed out, “Trying to set it up, but it is difficult to reach MBC patients.”

When asked, “In your opinion, what could your local breast cancer support or advocacy group do better (if anything) to support women with MBC?”, people responded:

To organize more and to be more supportive. Not just breast cancer but for MBC too. To accept and to know about MBC.

A fully dedicated organisation at the national level with enough funds to deal with MBC patients at the end of life.

Hard to say. Many groups are small and it may be difficult for them to provide services for everyone as it is almost always done on a voluntary basis. However, I would like to stress the importance of always including women with MBC and not excluding them because MBC is the triggering and scary part of breast cancer!

Dedicated follow up.

We have “Pink Space” in Tbilisi, for psycho-social support, but we need the same services in other regions.

Recruit an MBC patient and create a group, get involved in oncological clinics and raise awareness about the support patients can have from the group.

Break the taboo and stigma as people who are aware do not want to tell that they have MBC. Teach patients to live with the chronic disease. Start making patients feel good, not by fashion shows but by organising a tea, an aromatherapy session and try to make patients communicate between themselves. Teach patients on the value of exercise.

I feel that we have support if needed! There is always ways of improvement in workplace, training of all colleagues on how to deal MBC patients with more awareness and sensitivity.

For patients with serious conditions, there should be collaborations with countries with developed health systems in order to provide real support in prolonging life.

More relaxing stays or weekends in countryside.

For the moment, there is no patient contacting us, the medical and institutional staff gives a good support.

Get more women to join. They still don’t join the group in big numbers. But once they come, they are very happy that they did.

Besides technical and psychological support, we must support them concerning innovative therapies, their employment rights, payment during their treatment and absence from the work - in this moment it is 60% of their salary during sick leave.

Ensure more communication and support from the state and health care funds.

To do more would require more resources i.e., manpower and funding.

Develop societal awareness and education of MBC.

Realize that it really is a different group with different perspectives and needs. but also not just liaising from the group with primary breast cancer.

Spread more information. How can advocacy groups reach these patients? Patient data is not accessible.

Educational activities - information about innovations, support consultation 24 hours, information about pain medical services.

It could devote specific activities to women with MBC, different from those addressed to primary cancer patients.

Provide onco-psychological support.

We would need more resources (volunteers and/or employees) to fulfill different needs nationwide. Not every patient with MBC knows about us and our support.

We have no capacity for this great problem.

MBC patients need to learn to be resilient. Resilience is the buzz word at the moment, but I think having the motivation and living a happy journey are key too. I am aware that we have our bad days, but we compensate for them with the good days i.e., managing our energy, not our time.

Forty-three percent of respondents indicated that people with MBC in their country face a significant amount of stigma, 36% said they did not and 20% didn't know.

Ninety percent said there is a need for better understanding of MBC by the public. When asked, "What do they need to know?", people responded:

Even if there is some progress in understanding this particular disease on the long term, a big effort must be done at all stages of the disease to give hope and long-term visibility to the general public.

In the public eye breast cancer is the "good cancer" that "no-one" dies from anymore. It's pink, it has a happy ending and the narrative is that you get BC, go through surgery and chemo, post happy stories from a pink ribbon 5K with a bald head and then everyone cheers and you are expected to go back to normal! This view of breast cancer is very excluding for MBC-patients (and other struggling survivors) and there is no urgency for providing services or donating towards research for MBC. Also many politicians and other decision makers are oblivious about MBC and this has impact on public funding.

Information on life expectancy, advice against stigma and fear, support for caregivers.

We need many more advocacy meetings with information campaign, media support with MBC patients' stories, patient education and awareness.

The public need to change the attitude that most of society has, that these women have nothing to expect. Quality of life and survivorship are meanings not well established in people's consciousness. New drugs, clinical trials are very promising and it is not rare anymore that a woman with bone metastasis may live for more than a decade with stable disease.

We need many more advocacy meetings with information campaign, media support with MBC patients' stories, patient education and awareness.

An MBC patient, who is a survivor, could be in better health than somebody with other illnesses. People have to understand that.

There are people with special needs who can integrate into society taking into account the illness and reduced work capacity, the need for medical recovery (lymphedema) and psychological counseling.

A lot has been done but still, probably better communication and cooperation between oncologists and patient organisations.

That once the patient gets MBC diagnosis that doesn't mean death. That there are more and more options for treatment.

Lay public must understand that current approach to metastatic disease, although it is incurable, is to control it by innovative treatments in that way prolonging life and improving quality of life of the patients. More social programs and events in which MBC patients can be included are needed.

The public does not understand other than material and financial needs, not the emotional side and the need to ensure good quality of life, including professionally.

Better understanding the nature of disease, education about new drugs, better involvement in everyday life, better support in how to help patients with their everyday needs.

Make sure that everyone understands that not all cancers can be cured. Too many interviews, books, ... focus on 'after cancer'. Generic for all cancers, not only breast cancer.

That MBC patients are dealing with facing life-long treatment. That approx. 20-30% of BC cases will proceed to MBC, maybe also years later. Pink October leaves the public with the impression that BC can be prevented and cured. This sadly leads to MBC patients feeling very alone and guilty.

That people with metastatic breast cancer can sometimes live longer even though they no longer get better. That you can't always see that people are sick. That people with metastases receive many different treatment / lines and are therefore constantly busy adjusting to their treatment.

Information on innovative treatments, opportunities to live with the metastatic disease, integration into society, the labor market, current medical opportunities to ensure quality of life.

That MBC can be a chronic condition, not always an invalidating illness.

That it can be treated, patients with MBC should not lose belief in their own "tomorrow" and fair treatment.

Psychological assistance programs, educational films about the success of women survivors of breast cancer, MBC, information materials.

Quality of life improves for people with MBC with better treatment and better organisation of services.

They should learn that it's a long and lasting treatment.

Thirty-five percent of respondents indicated that MBC Awareness Day has been declared by a patient organization(s) in their country.

A very high 79% indicated that they think EUROPA DONNA – The European Breast Cancer Coalition should declare October 13th as MBC Awareness Day, but some have reservations or strongly disagree:

Very important for the MBC patient to have their own day to celebrate and the European day will give a better view.

On the one hand it is close to Breast Health Day (15/10) and is important to honor these two days closely. On the other hand it may cause frustration to public.

We need to light up in multiple colours as Metavivor is doing in the US.

I believe that there should not be too many awareness days because it deflects from the significance of breast cancer awareness month that should tie in my opinion all the relevant activities and aspects.

Belgium has a generic cancer day. I don't think there should be a specific awareness day for every type of cancer.

This would be a great initiative - many MBC patients do not feel included by 'Pink October' campaigns and question the pink washing that is attached.

People were then asked what is lacking in their country that they believe should be advocated for regarding MBC. They were asked to tick the four most important issues for their country. **Responses were:**

National Cancer Registry that includes MBC on secondary diagnosis	64,29%
Support for partners/carers of women with MBC	57,14%
Financial support for those undergoing treatment	46,43%
Access to the best, most effective treatments financed by the public health system	39,29%
Need fot better understanding of the disease from the lay public	39,29%
Better communication and engagement between patients and doc	39,29%
Service counselling and information availabity through treatment centres	35,71%
National guidelines for the treatment of MBC	28,57%
Employment support for those undergoing treatment	25,00%

Conclusions

Progress continues to be made in MBC services in Europe. The latest treatments and drugs are available in 83% of countries polled. Two-thirds of countries have widespread testing for genetic mutations such as BRCA. Furthermore, patient organisations are stepping up at the local and national levels to provide much needed education and services for people with MBC. Almost three-quarters indicated that people with MBC participate actively in their local breast cancer support or advocacy group activities/meetings. And nearly all of the patient organisations polled provide critically important information and services regarding MBC, including emotional support, practical guidance, follow-up, end-of-life care, work and financial/legal guidance, support groups, online/telephone access to healthcare professionals that answer questions, 13th October (MBC awareness day), and physiotherapy for lymphedema.

In spite of the progress made, daunting challenges still exist. Even though the latest treatments and drugs are generally available in European countries, issues remain as to when they become available, slow reimbursement, and, in some countries, patients having to cover the costs, which are considerable.

Although there is generally widespread testing available for genetic mutations such as BRCA, it seems few countries offer **genomic tests** at MBC diagnosis and, what's more, MBC advocates have low awareness of their state of availability. More education in the MBC advocacy community needs to take place on this topic.

Furthermore, **clinical trials** for people with MBC are only available in about half of the countries, and people who do not live close to the host centres cannot easily access them.

Psycho-oncology services are described as available but limited for MBC patients; only 43% of respondents to this survey claim that they are widely available and free of charge. In addition, partners, carers, children and family members of people with MBC are not felt to be supported by the vast majority.

Fifty-three percent of MBC advocates polled feel that **treatment and services** for people with MBC in their country are not adequate today. They cite varied and complex issues, such as the need for: reimbursement of new treatments, navigation nurses/breast care nurse specialists, the latest generation of drugs and appropriate testing protocols, psycho-oncologists and the prioritization of psycho-oncology, rehabilitation and financial support, new innovative therapies and clinical studies, a better care path, access to a multi-disciplinary team, adequate government budget financing for oncology, and equal access to health services. Additionally, several different respondents pointed out that patients need to be made aware that they have MBC in the first place, which is a major red flag for the need for improved doctor/patient communication and shared decision-making. People also talked about the difficulty faced by patient groups in reaching people with MBC to avail them of services which could be of help. Almost all of the advocates polled indicated that there is a need for better understanding of MBC by the public, and about half claimed that people with MBC in their country face a significant amount of stigma due to their disease.

Legislation protecting the right to work, the right to access insurance, the right to be forgotten/remembered, social/economic support continues to lag, and advocates do not seem to have strong awareness of this area. This can be developed through additional educational programming by EUROPA DONNA – The European Breast Cancer Coalition (N.B. it has been covered many times already).

Respondents cited as the most important issues to be advocated for in their country as:

1. National Cancer Registry that includes MBC on secondary diagnosis
2. Support for partners/carers
3. Financial support for those undergoing treatment
4. (Three-way tie) Access to the best, most effective treatments financed by the public health system; Better communication and engagement between patients and doctors; Need for better understanding of the disease from the lay public

Moving forward, Europa Donna – The European Breast Cancer Coalition plans to take the results from this survey and apply them on the European level to a social media campaign and other targeted programming to increase our support of the excellent MBC advocacy work already taking place and patients organisations on this continent.

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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