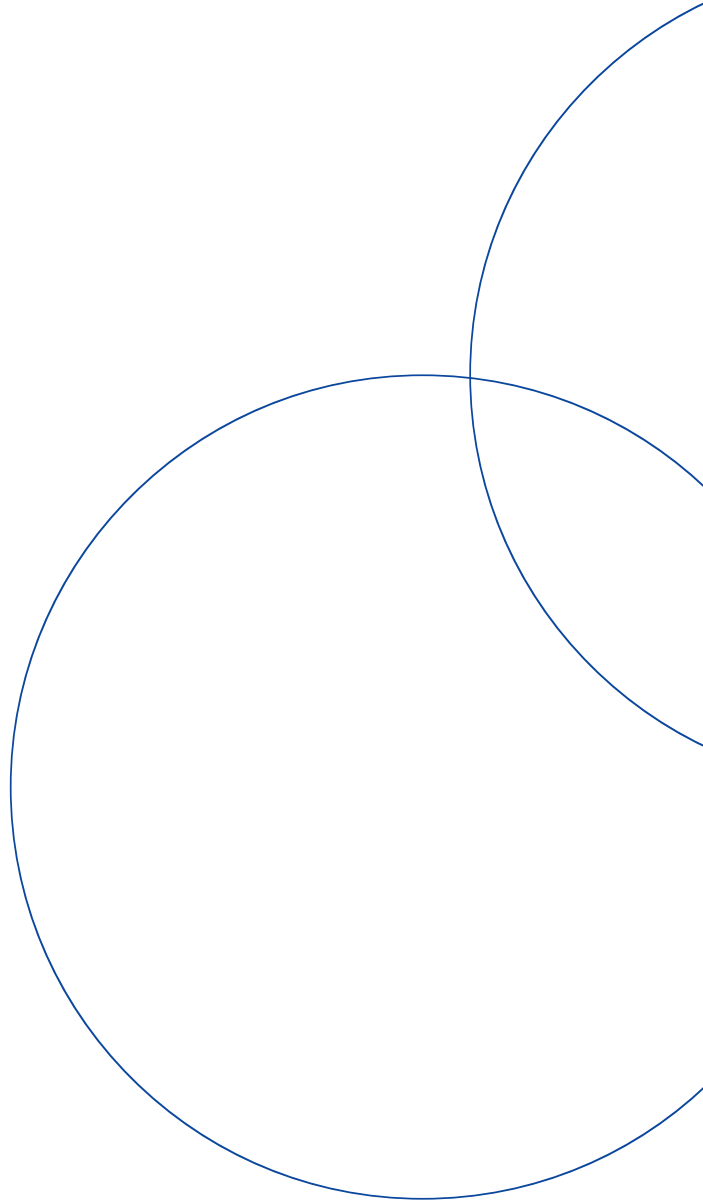


EUROPA DONNA

THE EUROPEAN BREAST CANCER COALITION

White Paper

Cancer and family planning

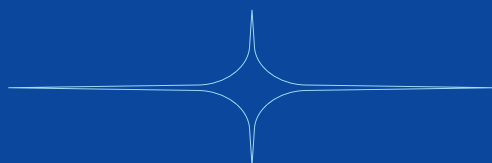


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About EUROPA DONNA

EUROPA DONNA – The European Breast Cancer Coalition – is an independent, non-profit organisation whose members are affiliated groups from countries throughout Europe. **EUROPA DONNA** works to raise public awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optimal treatment and care and increased funding for research. Member countries currently number 47.



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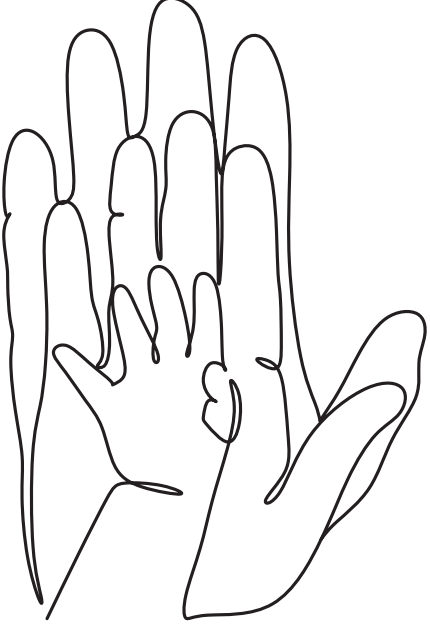
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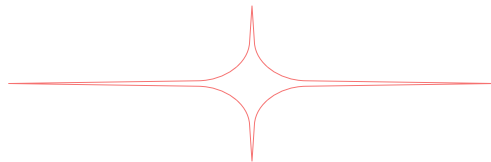
Introduction



In recent decades, the length of life of the European population has been increasing. People are living longer and healthier lives, thanks in part to advances in research, medical treatments and cures, social and economic conditions, and also thanks to increased self-awareness and health knowledge. Nevertheless, cancer represents one of the most important causes of mortality and morbidity in Europe with more than 3.7 million new cases and 1.9 million deaths each year according to WHO. It is the leading cause of death among Europeans below 65 years of age.

These numbers have a huge impact on countries' health and social systems and economies.

Breast cancer is a significant health concern affecting women in Europe. The incidence of breast cancer has been steadily increasing in Europe, with over 355,000 new cases diagnosed in 2020 alone[1]. An estimated 23% of breast cancer cases in Europe[2] occurred in women when they are younger than 50 years old[3] as shown in the table below.

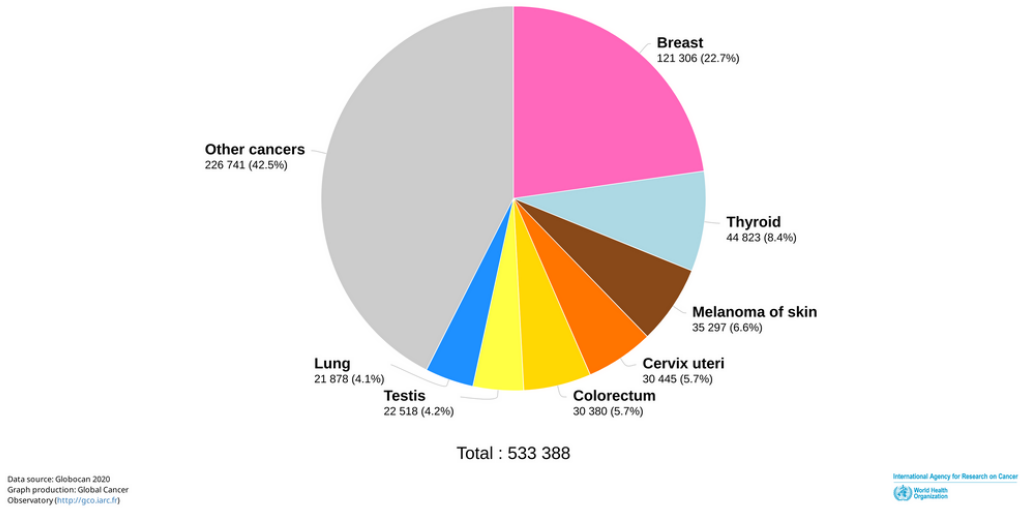


[1] Joint Research Centre - https://joint-research-centre.ec.europa.eu/jrc-news-and-updates/2020-cancer-incidence-and-mortality-eu-27-countries-2020-07-22_en

[2] "Europe" is considered as WHO Europe region.

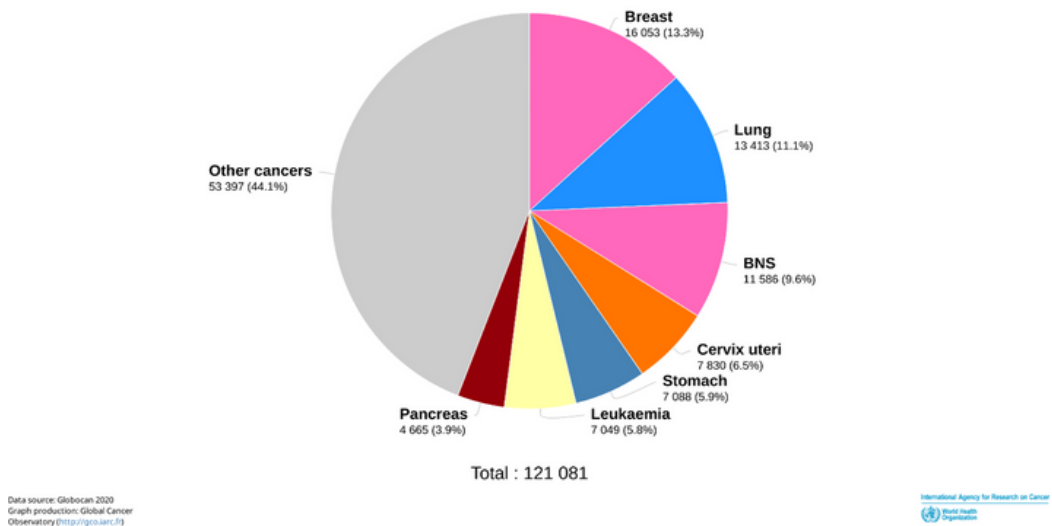
[3] Europa Donna - The European Breast Cancer Coalition - <https://www.europadonna.org/breast-cancer/> and https://gco.iarc.fr/today/online-analysis-pie?v=2020&mode=cancer&mode_population=continents&population=900&populations=923&key=total&sex=0&cancer=39&type=0&statistic=5&prevalence=0&population_group=0&ages_group%5B%5D=0&ages_group%5B%5D=9&nb_items=7&group_cancer=1&include_nmsc=1&include_nmsc_other=1&half_pie=0&donut=0#collapse-group-1-2

Estimated number of new cases in 2020, WHO Europe (EURO), both sexes, ages 0-49



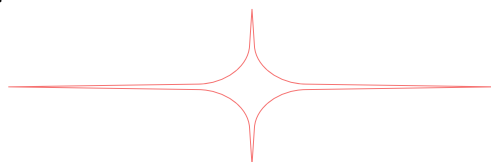
The mortality rate represents more than 13% of all breast cancer cases diagnosed in women younger than 50 years of age in 2020 as per Globocan data in the diagram below.

Estimated number of deaths in 2020, WHO Europe (EURO), both sexes, ages 0-49



At the same time, in recent decades, the implementation of organized population-based screening programmes has increased the early diagnosis rate and the advancement of research and available oncological treatment have allowed a higher rate of survival after breast cancer.

Young women (and men) diagnosed with breast cancer face a unique set of challenges, including difficulties with fertility preservation and family planning. Among female cancer survivors, overall pregnancy rates (adjusted for female age and education level) are around 40% lower than in the general population[4]. In general, up to 80% of cancer survivors are affected by reduced fertility arising from their cancer treatment[5].



[4] Peccatori et al., 2013
[5] Linkeviciute et al., 2014

This White Paper highlights the difficulties that people of reproductive age diagnosed with breast cancer face when it comes to fertility preservation and family planning and suggests concrete actions for policymakers to improve fertility preservation and family planning options for breast cancer patients in Europe.

This document follows the policy event “Cancer and Family Planning” organised by Europa Donna – The European Breast Cancer Coalition and hosted by MEP Frances Fitzgerald (EPP) at the European Parliament on February 28th, 2023. Stella Kyriakides, European Commissioner for Health and Food Safety and former President of Europa Donna attended in person and delivered a very compelling keynote speech. The panel of experts consisted of Tanja Spanic, Europa Donna Coalition’s President; Fedro A. Peccatori, Director of the Fertility and Procreation Unity at European Institute of Oncology of Milan (IEO) and Scientific Director at the European School of Oncology (ESO); and Katie Rizvi, Youth Cancer Europe’s Executive Director.

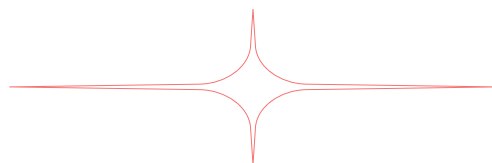


Cancer treatment and fertility preservation

Scientific studies conducted on issues related to fertility for breast cancer patients showed that about 73% of young people[6] diagnosed with breast cancer are concerned about how it will affect their fertility[7] and, for this reason, about 30% of them does not comply with their treatment due to fear of missing the chance to conceive.

Consequently, only around 5% of breast cancer patients have a pregnancy after diagnosis and this is largely due to lack of reliable information and consequent misconceptions around being able to carry on the pregnancy[8].

It is true that cancer treatment may affect future fertility of patients in childbearing age in several ways[9].



[6] For the purpose of this paper, “young” people shall mean people aged 18 to 49 or men and women of reproductive age.

[7] Partridge AH, Gelber S, Peppercorn J, Sampson E, Knudsen K, Laufer M, Rosenberg R, Przepyszny M, Rein A, Winer EP. Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol*. 2004 Oct 15;22(20):4174-83. doi: 10.1200/JCO.2004.01.159. PMID: 15483028.

[8] Peccatori et al., 2023

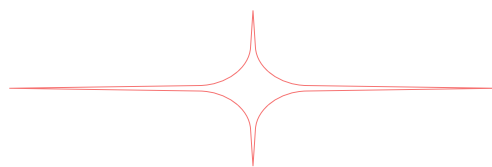
[9] Di Tucci C, Galati G, Mattei G, Chinè A, Fracassi A, Muzii L. Fertility after Cancer: Risks and Successes. *Cancers (Basel)*. 2022 May 19;14(10):2500. doi: 10.3390/cancers14102500. PMID: 35626104; PMCID: PMC9139810.

Some treatments, namely chemotherapy and radiotherapy can cause loss of primordial follicles, thus reducing the ovarian reserve and leading to fertility reduction or infertility in cancer patients. As literature on the topic explains, this risk may significantly vary and depends on the kind medication used, the dosage, and the age of the patient at the time of treatment. For example, the use of adjuvant chemotherapy including alkylating agents for a total duration of 6 months reduces significantly the ovarian reserve in a person of 40 years of age or older, causing menopause in around 40% of cases, while in women younger than 35 years the risk of early menopause is more limited (around 10%).

The other problem is the postponement of pregnancy for the prolonged endocrine treatment needed to reduce the risk or relapse or metastases in endocrine responsive breast cancer. In this case, the treatment is not gonadotoxic per se, but it is the older age at pregnancy that impairs the chances of getting pregnant[10]. Of note, a recently published paper[11] will probably change the clinical scenario, allowing a temporary interruption of endocrine treatment after 18-30 months to seek pregnancy.

Data from this and other studies confirm that pregnancy after breast cancer is safe and that is not associated with an increased risk of relapse or with fetal malformations. Moreover, if women are motivated and establish a therapeutic alliance with their doctors, the rate of successful pregnancies after breast cancer can be as high as 65% (ref Partridge Niman Ruggeri et al NEJM).

Fertility preservation refers to the various techniques available to help patients preserve their fertility before undergoing cancer treatment. For young women and men with breast cancer, fertility preservation may seem to be particularly challenging due to the fact that, often, cancer treatment needs to start as soon as possible.



[10] Fertility preservation and post-treatment pregnancies in post-pubertal cancer patients: ESMO Clinical Practice Guidelines †. Lambertini M, Peccatori FA, Demeestere I, Amant F, Wyns C, Stukenborg JB, Paluch-Shimon S, Halaska MJ, Uzan C, Meissner J, von Wolff M, Anderson RA, Jordan K; ESMO Guidelines Committee. Electronic address: clinicalguidelines@esmo.org. Ann Oncol. 2020 Dec;31(12):1664-1678. doi: 10.1016/j.annonc.2020.09.006. Epub 2020 Sep 22. PMID: 32976936

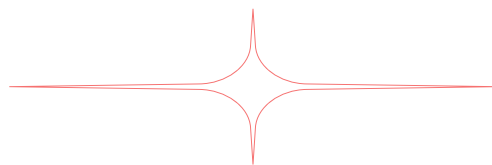
[11] Interrupting Endocrine Therapy to Attempt Pregnancy after Breast Cancer. Partridge AH, Niman SM, Ruggeri M, Peccatori FA, Azim HA Jr, Colleoni M, Saura C, Shimizu C, Sætersdal AB, Kroep JR, Mailliez A, Warner E, Borges VF, Amant F, Gombos A, Kataoka A, Rousset-Jablonski C, Borstnar S, Takei J, Lee JE, Walshe JM, Ruiz-Borrego M, Moore HCF, Saunders C, Bjelic-Radisic V, Susnjar S, Cardoso F, Smith KL, Ferreiro T, Ribí K, Ruddy K, Kammler R, El-Abed S, Viale G, Piccart M, Korde LA, Goldhirsch A, Gelber RD, Pagani O; International Breast Cancer Study Group; POSITIVE Trial Collaborators. N Engl J Med. 2023 May 4;388(18):1645-1656. doi: 10.1056/NEJMoa2212856. PMID: 37133584

One of the most common methods of fertility preservation is ovarian stimulation and egg retrieval. The procedure can be started any day of the menstrual cycle and usually lasts around 2 weeks. Recent data confirm that ovarian stimulation is not associated with worse oncological prognosis, even in patients with endocrine responsive breast cancer[12].

Another option for fertility preservation is ovarian tissue cryopreservation, which involves removing and freezing a piece of ovarian tissue before cancer treatment. However, this technique implies a surgical operation in general anesthesia and the surgical re-implantation of the ovarian tissue when menopause occurs. Thus, it has limited indication in breast cancer patients. (Lambertini, Peccatori, Demesteere, *Annals of Oncology*).

For what concerns diagnosis of cancer (not breast cancer) in children and pre-puberal patients, there are very limited available techniques to preserve fertility. In fact, ovarian tissue reimplantation is the only fertility preservation technique that can be used to preserve prepubertal fertility[13]. Therefore, young women who survived childhood cancer face even more challenges in planning a family after treatment.

For the above reasons, all cancer patients, including pediatric patients, should be presented and duly informed about all available fertility preservation options at diagnosis stage (and, when necessary, adoption options at later stage). That being said, fertility preservation options must be regarded as a civil right as well as sexual and reproductive health right - that needs to be guaranteed across all European countries and beyond. The right to reproduction is also protected under International Law. In fact, the United Nations Universal Declaration of Human Rights proclaims that men and women have the right to found a family[14]. Moreover, the United Nations International Covenant on Civil and Political Rights states that “[t]he right ... to found a family shall be recognized.”[15] The European Convention on the Protection of Human Rights and Fundamental Freedoms also adheres to this[16]. In short, the right to become a parent is a nearly universally acknowledged right.



[12] [Safety of fertility preservation techniques before and after anticancer treatments in young women with breast cancer: a systematic review and meta-analysis](#). Arecco L, Blondeaux E, Bruzzzone M, Ceppi M, Latocca MM, Marrocco C, Boutros A, Spagnolo F, Razeti MG, Favero D, Spinaci S, Condorelli M, Massarotti C, Goldrat O, Del Mastro L, Demeestere I, Lambertini M. *Hum Reprod*. 2022 May 3;37(5):954-968. doi: 10.1093/humrep/deac035.PMID: 35220429

[13] Di Tucci C, Galati G, Mattei G, Chinè A, Fracassi A, Muzii L. Fertility after Cancer: Risks and Successes. *Cancers (Basel)*. 2022 May 19;14(10):2500. doi: 10.3390/cancers14102500. PMID: 35626104; PMCID: PMC9139810.

[14] Universal Declaration of Human Rights, G.A. Res. 217A(III), art. 16(1), U.N. GAOR, 3d Sess., U.N. Doc. A/810 (Dec. 10, 1948).

[15] International Covenant on Civil and Political Rights art. 23(2), Dec. 16, 1966, 999 U.N.T.S. 179

[16] European Convention for the Protection of Human Rights and Fundamental Freedoms art. 12, Nov. 4, 1950, 213 U.N.T.S. 222

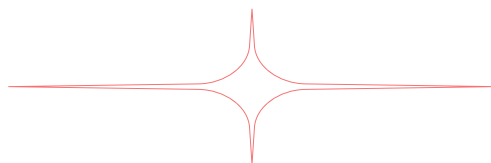
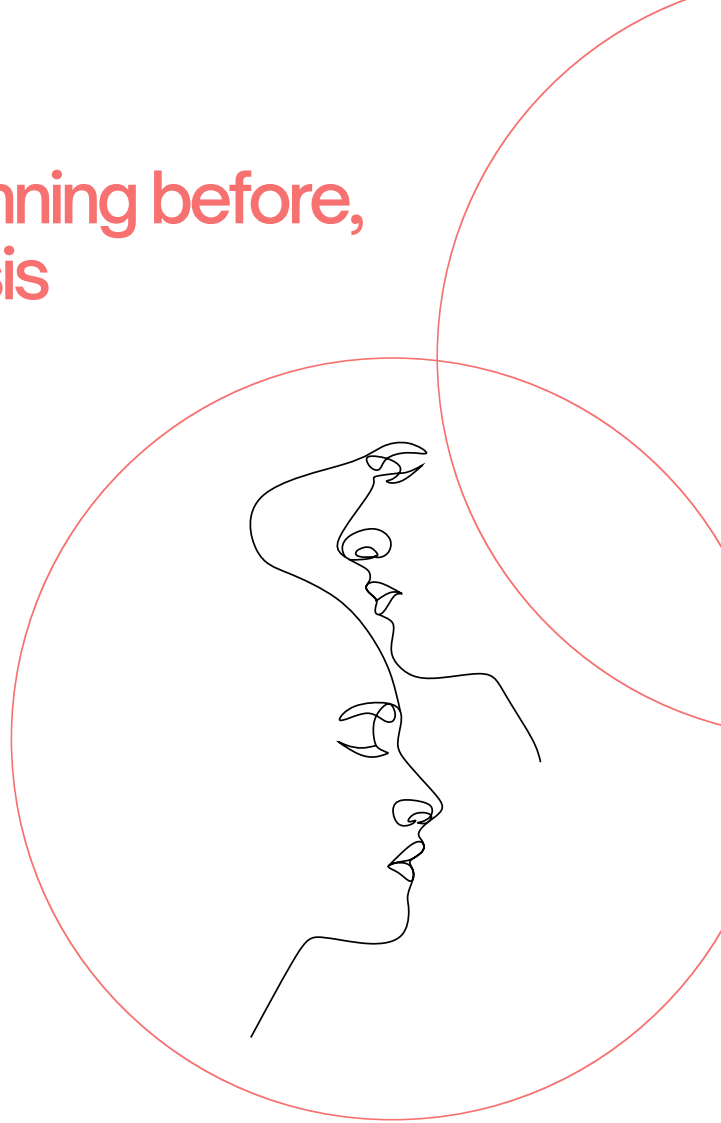
* Sexuality and family planning before, during and after diagnosis

Some treatments and drugs prescribed to fight cancer may affect the sexual life of a patient.

In the last four decades, there has been a rising trend of delaying childbearing[17] across all countries in Europe. This is due to a variety of reasons linked to socio-economic and cultural factors such as high-pressure working conditions, lack of social childcare support, etc.

There are two main concerns young breast cancer patients need to face: the possible negative effects of treatment on a future pregnancy, and the consequences pregnancy may have on the patient[18].

For young women who have already completed breast cancer treatment and are ready to start a family, family planning can also be challenging. In fact, only 5% of patients with breast cancer have a pregnancy after diagnosis[19]. This incredibly low percentage is rooted in a variety of reasons, such as the age of the patient at diagnosis, chemotherapy toxicity, prolonged duration of endocrine treatment, limited access and use of fertility preservation across European countries, and, importantly, a general fear of pregnancy by both patients and physicians (see also above).



[17] Peccatori F.A., Azim H.A., Jr., Orecchia R., Hoekstra H.J., Pavlidis N., Kesic V., Pentheroudakis G., ESMO Guidelines Working Group Cancer, pregnancy and fertility: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Ann. Oncol.* 2013;24: 160-170.

[18] Di Tucci C, Galati G, Mattei G, Chinè A, Fracassi A, Muzii L. Fertility after Cancer: Risks and Successes. *Cancers (Basel)*. 2022 May 19;14(10):2500. doi: 10.3390/cancers14102500. PMID: 35626104; PMCID: PMC9139810.

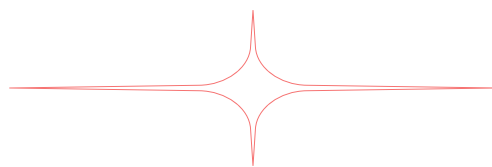
[19] Anderson RA, Brewster DH, Wood R, Nowell S, Fischbacher C, Kelsey TW, Wallace WHB. The impact of cancer on subsequent chance of pregnancy: a population-based analysis. *Hum Reprod.* 2018 Jul 1;33(7):1281-1290. doi: 10.1093/humrep/dey216. PMID: 29912328; PMCID: PMC6012597.

One of the biggest concerns is the risk of recurrence of breast cancer and the consequent uncertainty about the future. Women who have had breast cancer fear that they are at higher risk of developing a new cancer or having a recurrence of their primary cancer. These feelings often lead to anxiety and depression and can make it difficult to decide when to start a family or whether to have more than one child. They also have a negative impact on women's willingness and ability to have a normal social life and to seek out or continue relationships.

Moreover, it is common for patients and survivors or people living after breast cancer diagnosis, as a consequence of a traumatic event, to feel less confident with their body even if they do not undergo lumpectomy or mastectomy. General frustration with the body and lowered self-esteem may change the patients' ability to enjoy sexual life, thus leading to psychosexual disfunctions/disorders such as a diminished sexual appetite.

In 2022, Youth Cancer Europe conducted a survey [20] among more than 600 cancer patients aged 15 to 39 at diagnosis to better understand young people's awareness of fertility preservation and its relationship to quality of life and mental health. The survey revealed that about 28% cancer patients did not discuss medical options for fertility preservation with their healthcare provider, with the Eastern European Countries reporting the lowest rates of involvement in fertility discussions. Furthermore, respondents who were not informed about available fertility services reported the lowest quality of life, fertility-related concerns greatly impacting their level of anxiety and depression[21].

As a result of another survey conducted in 2004 and shown at Europa Donna Policy Event at the European Parliament in February 2023 by Dr. Peccatori[22], most of young cancer patients are concerned about their fertility (73%) and 29% of the respondents (657 patients, median age 32.9 years) did not comply with their treatment because of fear of possible fertility issues.



[20] Survey on Awareness and Accessibility to Fertility Preservation Procedures in Europe, 2022, YCE; <https://osf.io/t9h82/>

[21] Survey on Awareness and Accessibility to Fertility Preservation Procedures in Europe, 2022, YCE; <https://osf.io/t9h82/>

[22] Partridge AH, Gelber S, Peppercorn J, Sampson E, Knudsen K, Laufer M, Rosenberg R, Przepyszny M, Rein A, Winer EP. Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol*. 2004 Oct 15;22(20):4174-83. doi: 10.1200/JCO.2004.01.159. PMID: 15483028.

Quality of life

Fertility preservation is an important quality of life issue for cancer patients of all ages.

Female and male identity, sexuality and fertility issues as a consequence of a cancer diagnosis can have a strong negative impact on quality of life. The diagnosis may have devastating effects on the psychosocial capacities of every human being and, in addition, knowing that therapy may endanger one's fertility or lead to infertility is another huge cause of suffering, as being able to have a family is commonly considered crucial to having a "normal life".

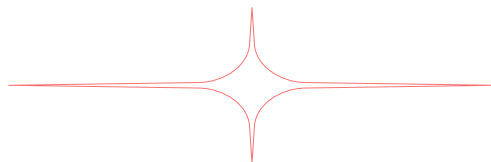


Fertility preservation methods such as oocyte cryopreservation, embryo cryopreservation, and sperm collection before therapy are available; however, they are not equally accessible to all patients due to prohibitive costs and limited availability.

Young women with breast cancer face a range of emotional and psychological challenges, and fertility preservation and family planning can add to these challenges. It is important for healthcare professionals to provide support and resources to help these women navigate these issues.

It has been suggested that fertility impairment might be considered one of the most life-altering late effects of cancer treatment, affecting the survivors' body image, sexuality, dating relationships, marriage patterns and sense of wellbeing[23].

For this reason, onco-fertility is gaining more and more attention at all levels, from scientific and medical to civil right and policy perspective at national and European level.

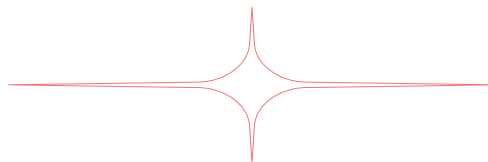


[23] Levine, Jennifer M., et al. "Fertility and Sexuality." Paediatric Psycho-Oncology: A Quick Reference on the Psychosocial Dimensions of Cancer Symptom Management (2015).

In February 2022, the European Parliament adopted a text “*Strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy*” stating that the Commission and the Member States should *plan actions that promote, in the context of care and treatment, greater attention to the protection of patients’ fertility, in particular in the case of paediatric and juvenile cancers*[24]. Moreover, the text adopted by the European Parliament *[s]trongly urges the Member States to ensure that all cancer patients are fully informed about the possibility of fertility preservation procedures prior to the start of active treatment; calls for the development of guidelines at EU level for health professionals, defining the age at which cancer patients should be informed about the availability of reproductive health procedures; encourages, furthermore, the Member States to make provision for all cancer patients covered by compulsory national health insurance to be reimbursed for such services by national health insurance schemes*[25].

Onco-fertility counselling is recommended at the earliest opportunity and prior to cancer treatment, to help patients make informed decisions on pursuing fertility preservation. Currently, however, such discussions are not being routinely held[26].

For all the above reasons and more, Multi-Disciplinary Teams (MDTs) are of fundamental importance in providing a full support to patients in all aspects of life after diagnosis. One resource which can be particularly beneficial is an onco-fertility specialist. Onco-fertility specialists can help patients understand their options for fertility preservation, and provide guidance on family planning before, during and after cancer treatment. Nevertheless, fertility options are not accessible everywhere and, if they are, their costs pose a significant financial burden on patients. If national health systems or insurance companies do not cover or reimburse oncologic fertility preservation procedures, these options cannot be considered by the vast majority of patients as shown in the table below[27].



[24] European Parliament 2019-2024 TEXTS ADOPTED P9_TA(2022)0038 Strengthening Europe in the fight against cancer European Parliament resolution of 16 February 2022 on strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy (2020/2267(INI)), point 69.

[25] European Parliament 2019-2024 TEXTS ADOPTED P9_TA(2022)0038 Strengthening Europe in the fight against cancer European Parliament resolution of 16 February 2022 on strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy (2020/2267(INI)), point 115.

[26] Dolmans M., Lambertini M., Tryde Macklon K., Almeida Santos T., Ruiz-Casado A., Borini A., Bordes V., Frith L., Van More E. Germeyer A . EUropean REcommendations for female FERtility preservation (EU-REFER): A joint collaboration between oncologists and fertility specialists. Critical Reviews in Oncology/Hematology; Volume 138, June 2019, Pages 233-240

[27] DOI: 10.1200/JGO.2016.008144 JCO Global Oncology no. 6 (2017) 331-344. Published online June 17, 2017.

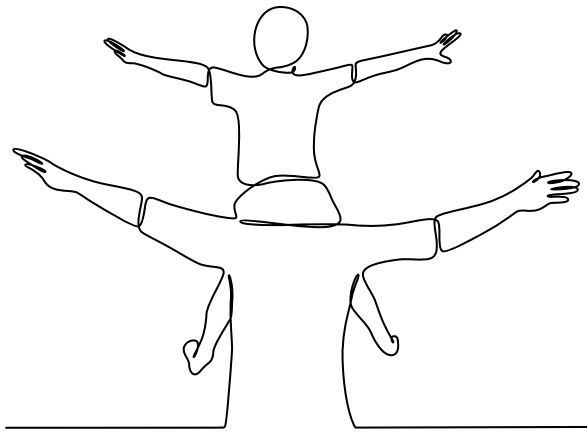
Regional Estimates of the Potential Out-of-Pocket Financial Burden of Fertility Preservation Procedures for Patients With Cancer

Continent and Country	Coverage of Fertility Preservation Procedures	Rank of Cost to Patient
 Austria	Reimbursement differs from province to province. Generally, storage is not covered, which in Innsbruck amounts to 310 USD per year. Ovarian tissue cryopreservation is sometimes reimbursed by insurance, but this differs among insurance companies. Cryopreservation of oocytes and spermatozoa are not covered and must be entirely funded by patients. IVF for the generation of blastocysts may be paid for the IVF Fund if the couple has an indication (pathospermia, endometriosis, tubal factor, or PCO), but this is handled differently depending on the institution.	\$\$
 Belgium	Fertility preservation procedures are free to patients younger than 18 years because techniques are still considered experimental for minors. Patients with cancer older than 18 years pay a reduced price (compared with patients without cancer) of approximately 560 USD out-of-pocket v several thousand USD. Embryo cryopreservation is fully reimbursed in all cases. The Minister of Healthcare announced in 2016 that partial reimbursement of fertility preservation procedures for patients with cancer would begin in 2017.	0-\$\$
 Denmark	Insurance covers the cost of ovarian tissue cryopreservation.	0
 France	French social security covers all costs (whatever the technique used) for patients with a medical indication for fertility preservation. Fertility preservation without medical indication is not authorized.	0
 Germany	Insurance partially covers costs.	\$\$
 Poland	No coverage. Cost to the patient is approximately 670 to 2,780 USD for all cryopreservation procedures. Consultation and medical examinations are reimbursed under the Polish National Health Service, but ART and cryopreservation procedures, such as transplantation, are not covered. The cost of the medical consultation for a patient interested in fertility-preserving methods is reimbursed on the basis of their health insurance.	\$\$\$-\$\$\$\$
 Portugal	Consultations, medical examinations, technical procedures, and cryopreservation procedures are all covered under the Portuguese National Health Service. Medication is covered at 69%, so patients must pay for the other 31% (cost to the patient for medication is approximately several hundred USD).	0-\$\$
 Netherlands	Most costs are reimbursed by insurance, but experimental procedures, such as cryopreservation of ovarian tissue or testicular stem cells, is paid for by the hospital.	0
 Russian Federation	Not coverage. The first 12 months of tissue storage costs are approximately 220 USD. For the second year on, costs are approximately 100 USD per year. Discounts are offered for long-term storage. Adolescents younger than 25 years are covered by charities.	0-\$\$\$
 Spain	Public insurance covers cryopreservation of eggs, sperm, and embryos as well as a limited number of cycles of assisted reproduction. Because ovarian cortex and immature testicular tissue cryopreservation are considered experimental procedures, they are covered by research grants.	0
 United Kingdom of Great Britain and Northern Ireland	State coverage for most options (although some restrictions on access exist) and partial research funding for experimental options (ovary and testis cryopreservation) are available.	0

Lack of insurance coverage poses a great barrier to patient access to onco-fertility care.

Support groups can also be valuable resources for young women with breast cancer. Peer support groups provide a safe and reassuring environment where women can connect with others who are going through similar experiences. These groups can offer emotional comfort, information, and practical advice and should be available to all patients from the offset, at the time of diagnosis.

Conclusion*



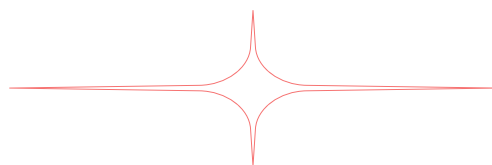
Young people with breast cancer in Europe face a range of challenges when it comes to fertility preservation and family planning. These challenges can have a significant impact on their emotional and psychological well-being.

Fertility after treatment is a major concern for young women with breast cancer. There is a need to educate and actively engage with young patients providing all necessary information on fertility issues and this should be done at the time of diagnosis, before undergoing treatment. There is also a great need for future research directed at preserving fertility for young breast cancer survivors[28].

All cancer patients of reproductive age as well as pediatric cancer patients should be adequately informed of the risk of fertility reduction and, in some circumstances, loss because of oncological treatments, and must be granted a timely and exhaustive explanation of all strategies available to reduce this risk as well as their costs. Finally, they should be provided the tools to undergo any such procedure, and professionally guided and safeguarded.

It is important for healthcare professionals to provide support and resources to help navigate fertility issues, including access to fertility specialists and support groups. By addressing these challenges, we can help improve the quality of life for young women with breast cancer in Europe.

As Dr. Peccatori pointed out, “equal and equitable access to fertility preservation should be warranted to all young oncological patients across the EU”.



[28] Partridge AH, Gelber S, Peppercorn J, Sampson E, Knudsen K, Laufer M, Rosenberg R, Przepyszny M, Rein A, Winer EP. Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol.* 2004 Oct 15;22(20):4174-83. doi: 10.1200/JCO.2004.01.159. PMID: 15483028.

In general, from a psychological perspective, surveys reveal that the fear of facing fertility problems is a major concern after a breast cancer diagnosis. However, this can be defeated by improving **awareness** and **education** about available therapies and possibilities during and after treatment for patients, patients representatives and health care providers.

In addition to the above, it is important to promote **research** on oncological outcomes after pregnancy in different patient populations, including those that must rely on Assisted Reproductive Technology (ART).

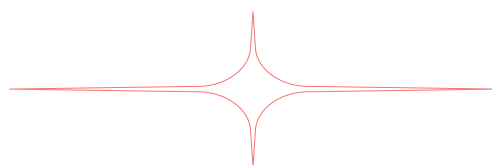
As last recommendation, Dr. Peccatori underlines the importance of establishing **onco-fertility units** within the comprehensive cancer centers or the cancer centers networks to address fertility concerns, family planning, contraception.

Even though the patient's community acknowledges that some commitment at a policy level has increased, fertility and cancer are still not highly placed on the European Union's political agenda[29], as Katie Rizvi, Youth Cancer Europe's Director, stated. In this sense, it is quite concerning that the European Commission's Europe's Beating Cancer Plan does not mention fertility issues.

After the publication of the Europe's Beating Cancer Plan, in February 2022, the European Parliament adopted a text "Strengthening Europe in the fight against cancer – towards a comprehensive and coordinated strategy" in which the European obligation to promote and protect the right to have a family for young patients is clearly defined and stated (see notes 21 and 22 of this document).

Introducing onco-fertility as a central aspect of the patients' care pathway is certainly a positive sign of an increasing attention to improve quality of life of people living with or after breast cancer by

However, it is not enough to ensure that this right is promoted and respected at a more practical level.



[29] <https://www.youthcancereurope.org/cancer-fertility-a-youth-cancer-europe-advocacy-project/>

* Call to Action

The relevance of the data presented by experts, the scientific community and patient advocates at the Europa Donna “**Cancer and Family Planning**” policy event at the European Parliament substantiates the need for legislation at EU and national levels, the need for clear guidelines and the need for available accessible and affordable reproductive health procedures in all European countries. There is a need for a clear commitment by EU Member States to implement national legislation aimed at promoting and protecting the right to reproduce and plan a family for all cancer patients.

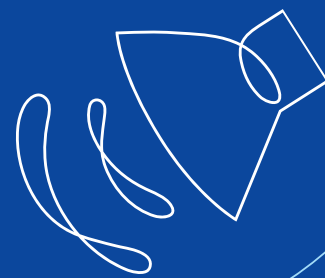
The policy event and this White Paper aim at reaching important milestones in (a) guaranteeing access to fertility preservation to all patients after a cancer diagnosis and (b) improving quality of life before, during and after cancer treatment. This goal can only be achieved by taking concrete actions.

In particular, our community of patients and scientists demands the following:

* Fertility becomes a central issue in guaranteeing quality of life of patients that is **acknowledged by the European Commission** by introducing the topic in its agenda and **in the Europe’s Beating Cancer Plan**.

* National legislations must require medical facilities to **fully inform** all cancer patients of both genders about the possibility of **fertility preservation procedures** regardless of their marital status and prior to the start of active treatment. The presented options must include in-vitro fertilization, oocyte and ovarian tissue cryopreservation, and all available possibilities including adoption. These legislations must **grant equal access** to fertility preservation for all young oncological patients at national level across the EU, regardless of age and financial means.

* There is need of setting up **Onco-fertility Units** within existing comprehensive cancer centers or cancer center networks, to address fertility concerns, family planning, contraception, as well as information on surrogacy and adoption.



✧ EU Member States should make a provision for all **fertility options** available for cancer patients to be **covered by the national health system** or **reimbursed** by national health insurance. This would also contribute to **address** the **existing inequalities** in accessing fertility options.

✧ In regard to European research on cancer, there is need for **adequate financial resources** to conduct more, in dept and specific research and collect better data on this subject, which is extremely relevant to all patients before and during their fertility age. Clinical Trials must include patients' perspective from the very design of the trial and **fertility related endpoints**.

In one sentence, we demand that the European policymakers implement all that is necessary for **people diagnosed with cancer not to be discouraged from having a family.**



The White Paper has been developed after an Europa Donna Policy event held at the European Parliament in February 2023, co-hosted by MEP Frances Fitzgerald and the Commissioner for Health and Food Safety Stella Kyriakides. It is aimed to address the significant challenges faced by young people, particularly women, diagnosed with breast cancer in Europe regarding their fertility preservation and family planning options. These challenges include concerns about the impact of cancer treatment on fertility, lack of awareness and access to fertility preservation methods, psychological and emotional distress, and the need for improved support from healthcare professionals.

The White Paper aims to highlight these issues and advocate for policy changes and legislative actions at both the European Union (EU) and national levels. It underscores the importance of recognizing fertility preservation as a fundamental right for cancer patients and seeks to promote and protect this right through concrete actions.

Ultimately, the goal of the White Paper is to improve the quality of life for individuals living with or after breast cancer by ensuring that they have the information, resources, and support they need to make informed decisions about their fertility and family planning options. It calls for a comprehensive approach involving EU Member States, healthcare institutions, and policymakers to address these important issues in the context of cancer care.



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