Gynaecological Cancers in Europe

Facts and figures 2024

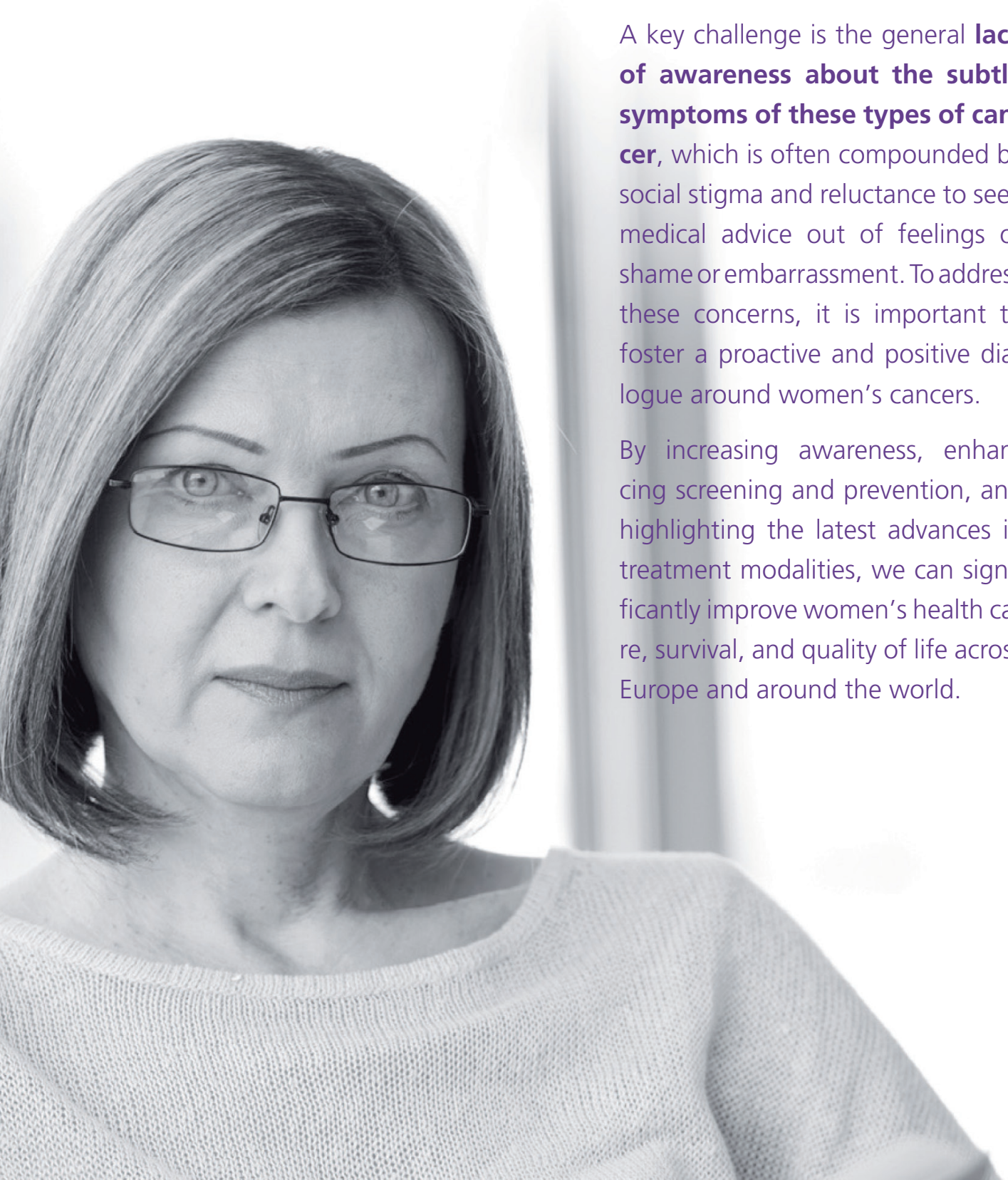
ENGAGe

ESGO | European Network of Gynaecological Cancer Advocacy Groups

Contents

Breaking the silence about women's cancers

Ovarian, uterine, cervical, and other gynaecological cancers are among the most prevalent cancers affecting women in Europe and worldwide. Despite this, such cancers often receive less attention than they deserve from the public and policymakers.



A key challenge is the general **lack of awareness about the subtle symptoms of these types of cancer**, which is often compounded by social stigma and reluctance to seek medical advice out of feelings of shame or embarrassment. To address these concerns, it is important to foster a proactive and positive dialogue around women's cancers.

By increasing awareness, enhancing screening and prevention, and highlighting the latest advances in treatment modalities, we can significantly improve women's health care, survival, and quality of life across Europe and around the world.

Facing the challenge together

Gynaecological cancers include common cancers of **ovary/fallopian tubes, the womb (uterus, endometrium),** and **cervix**, as well as rare cancers such as those affecting the **vulva and vagina**. In some countries, gynaecological cancer care also includes the management of breast cancer. As the leading European professional gynaecological cancer society, the European Society of Gynaecological Oncology (ESGO) shares the goal of patient groups to help and support women living with gynaecological cancers to obtain accurate, reliable, and timely information about their diseases, to understand treatment options, and to have access to the best possible care.

ESGO has established the European Network of Gynaecological Cancer Advocacy Groups (ENGAGe) to provide a platform for patient groups to share and exchange information, to stimulate the creation of new advocacy groups where there is a national and local need, and to join forces at the European level when appropriate. Progress and policy change can often only be achieved with a united voice across specific diseases: **this is why facing the challenges together is so important**. Furthermore, ESGO and ENGAGe have initiated a project to involve patient representatives in the design and implementation of clinical trials, to ensure that patients' perspectives are integrated into every aspect of the studies.

Closing the gap

Over the past decade, there have been many advancements in the diagnosis and treatment of certain cancers. However, women's cancers and rare malignancies often receive little attention in the areas of science, research, investmentand health policy. When it comes to these diseases, there remains a significant gap between what we know and what we do across the world and throughout Europe, especially regarding less common cancers.

Clinical guidelines continue to be critical in improving the care of gynaecological cancers, but the individual patient must always be the focus of the multidisciplinary and multiprofessional team. **Treatment decisions are influenced by the stage, the grade, and—increasingly—the genetic and molecular biological characteristics of a woman's cancer.** The opinion of the woman being treated should always be considered, and the patient–doctor relationship is a critical source of information as well as reassurance.

ESGO and ENGAGE are working intensively to develop European guidelines based on the results of recent research projects; however there are continuing inequalities both between and within European countries in relation to cancer risk, detection, treatment, and follow-up care. We all agree that we must improve the outcomes of women's gynaecological cancers in Europe and worldwide. We must ensure that the proven **benefits of cervical cancer screening and gender-neutral HPV vaccination** are extended to all countries, as well as that **every woman with ovarian cancer is referred to a specialized treatment centre**. To reduce disparities in cancer care, efforts are ongoing to address inequalities both within and between European countries, ensuring equal access to advanced screenings and treatments.

On the broader public health front, we must also raise awareness that **reducing the prevalence of obesity among women** will not only improve general health but also lower the risk of uterine, breast, and other cancers. Reliable public and patient information and education are often lacking. Patients and families need easy access to accurate and understandable information in all languages—across a variety of media channels. **Myths, misconceptions, and fake news must be dispelled to eradicate the stigma that is sometimes associated with gynaecological cancers.**

Education and resources

The molecular characterisation of tumours has advanced significantly, leading to a more precise categorization of ovarian and endometrial (womb) cancers into subtypes, each requiring tailored treatments and associated with varying outcomes. This progression highlights the necessity for certified gynaecological cancer centres, with specialised training and accredited programmes for professionals and institutions treating patients with such types of cancer.

There is increasing evidence supporting the notion that the **outcomes for women's cancer improve when treatment is provided by specialised teams in hospitals offering multidisciplinary approaches that combine surgical and medical expertise**. High-quality care involves not only access to advanced therapies and radiotherapy equipment, but also the presence of skilled medical and healthcare professionals, along with comprehensive rehabilitation and long-term follow-up.

Additionally, there is increasing emphasis on holistic care, where coping and support systems are integral and readily accessible to all patients and families. This type of care, which is delivered by healthcare professionals such as specialist support nurses and is made available within a reasonable distance of a patent's home, includes optimal psychosocial support at all disease stages and during follow-up. Such developments reflect a growing recognition of the complex needs of gynaecological cancer patients and the importance of addressing their needs through a comprehensive, patient-centred approach.

Knowledge and awareness

Ongoing research is critical to enhancing our understanding of how to effectively diagnose, treat, and follow up on each type of gynaecological malignancy, especially with the increasing availability of targeted therapies and novel treatments. **The role of patients in this process is evolving**; their involvement in clinical trials and in understanding the barriers to research participation are key areas of focus.

Patient organisations provide invaluable insights into disease impact, treatment efficacy, and quality of life, making their contributions vital for researchers and policymakers in shaping healthcare priorities and treatment recommendations. Moreover, educating patients and the general public about the **health benefits of quitting tobacco, maintaining a healthy weight, and engaging in regular physical activity** is increasingly recognized as essential for not only managing cancer but also for overall health and quality of life.

Patient advocacy and mobilising change

A shared advocacy agenda across gynaecological cancer patient groups will increase the attention of policymakers, help reveal inequalities, and give patients with gynaecological cancers higher priority on the European and global health agenda. Joint action will also afford patient groups the opportunity to synergise, to share best practices, and to improve knowledge of advocacy in patient organisations across specific diseases.

ESGO aims to support patients through ENGAGe by providing a platform for dialogue and action on key issues concerning gynaecological cancers in Europe and around the world.

Ovarian cancer

The ovaries are two oval-shaped glands located on either side of the uterus/womb and just below the opening of the fallopian tubes. They are responsible for producing eggs, or 'ova', and releasing the female sex hormones oestrogen and progesterone.

According to the International Agency for Research on Cancer, approximately 66,693 women were diagnosed with ovarian cancer in 2020, with approximately 44,053 associated fatalities. In Europe, ovarian cancer ranks as the eighth most common type of the disease and the fifth leading cause of cancer-related deaths among women [(6)].

In 2022, Europe recorded the highest rates of ovarian cancer incidence and mortality worldwide **(Figure 1)** [(5)]. These rates were notably higher in Central and Eastern Europe and lower in Southern Europe **(Figure 2)** [(8)]. A little less than 40% of women in Europe remain alive five years after being diagnosed with ovarian cancer **(Figure 3)** [(8)]. This survival rate is strongly influenced by the stage at which the cancer is detected, with advanced-stage diagnoses often having poorer outcomes.

Ovarian cancer is a complex entity that encompasses a range of histological types, each responding differently to treatment. The most common type, high-grade serous ovarian cancer, is often treated effectively with complex cytoreductive surgery, chemotherapy, and targeted maintenance therapies.

It is also important to note the relationship between ovarian cancer, primary fallopian tube cancer, and primary peritoneal cancer. The fallopian tubes, which connect the ovaries to the womb, can also be a primary site for cancer. Although previously considered exceedingly rare (1% of all female genital cancers), recent research suggests a closer link between ovarian and fallopian tube cancers. Many cases previously classified as ovarian cancer are now understood to have originated in the fallopian tubes. Consequently, the approach to diagnosing and treating primary fallopian tube cancer aligns closely with that for ovarian cancer. Understanding this connection is vital to accurate diagnosis and effective treatment.

Recent advances in ovarian cancer treatment have brought targeted therapies to the forefront, especially for patients with specific genetic profiles. Poly (ADP-ribose) polymerase inhibitors, commonly known as PARP inhibitors (such as olaparib, niraparib, and rucaparib), have become a game changer in managing high-grade ovarian cancer [(9)]. These drugs are particularly effective in patients with BRCA mutations or other specific genetic conditions. They work by targeting cancer cells' ability to repair DNA, making the cells more susceptible to damage and death.

For more detailed information on the causes, diagnosis, and treatment of ovarian cancer, refer to the fact sheet developed by ENGAGe, which covers each of the gynaecological cancers.

ENGAGe also developped a brochure on PARP inhibitors and their use in cancer treatment as well as a brochure on Genetic testing for women with cancer predisposing genes.

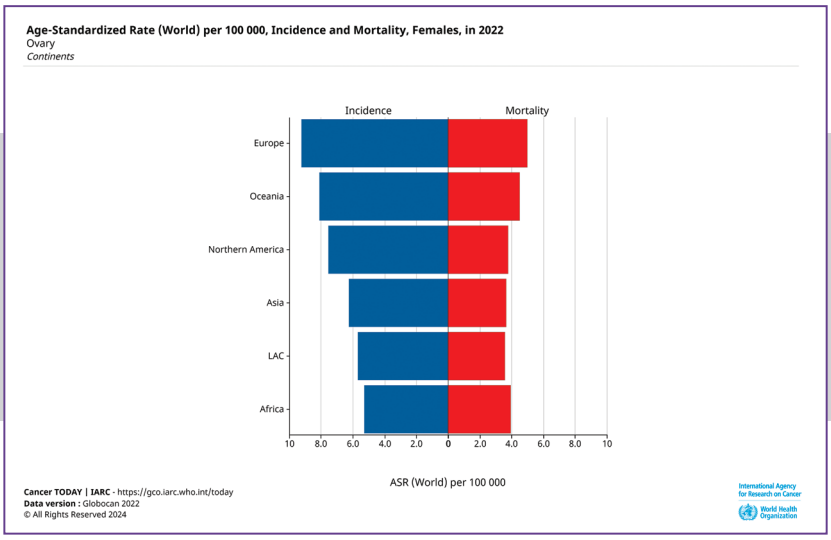


Figure 1: *Incidence and mortality rates of ovarian cancer by continent in women aged 0-85 in 2022, according to the World Health Organization (WHO) International Agency for Research on Cancer*

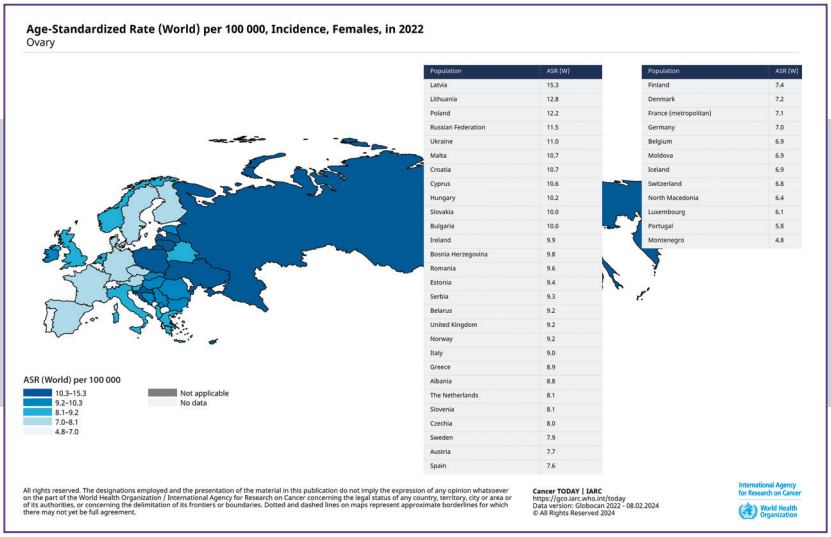


Figure 2: *Estimated incidence rates for ovarian cancer in Europe in 2022*

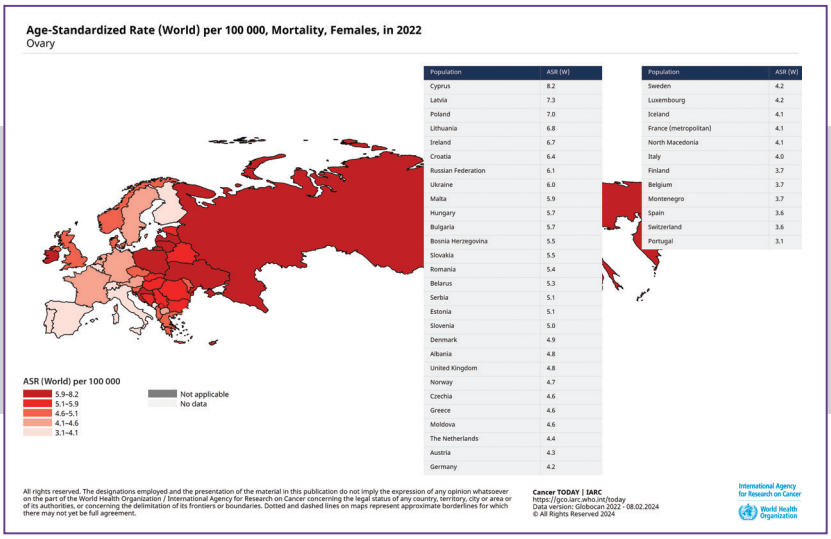


Figure 3: *Estimated Mortality Rates for Ovarian Cancer in Europe in 2022*

Endometrial cancer

The uterus, also known as the womb, is a key female reproductive organ where a baby develops during pregnancy. This hollow, muscular organ, connected to the cervix, comprises three distinct layers. The innermost layer, the endometrium, is primarily responsible for preparing to host a fertilized egg. In the absence of fertilization, the menstrual period occurs each month due to shedding of the superficial part of the endometrium.

While there are various uterine cancers, the majority originate in the endometrium's cells. These cancers, known as endometrial adenocarcinomas, develop from the lining of the womb [(16)].

The terms 'uterine cancer' and 'endometrial cancer' are often used interchangeably. Traditionally, endometrial cancer was classified according to histologic features into type I (more common, lower-risk, oestrogen-driven) and type II (less common, more aggressive, non-oestrogen-driven). However, this classification method failed to fully capture the complexity of neoplasms. The World Health Organization and the International Federation of Gynaecology and Obstetrics (FIGO) have since developed classifications that include molecular features for more objective, reproducible categorization. This helps inform prognosis and guide treatment decisions [(17,18)]. ESGO's guidelines strongly call for the implementation of modern molecular pathology to more accurately describe a patient's prognosis and to tailor therapy accordingly, including immunotherapy.

Significant risk factors for endometrial cancer include family history, environmental factors, obesity, and genetic predisposition, which accounts for approximately 2–5% of endometrial cancers. The most common hereditary predisposition for endometrial cancer is Lynch syndrome, which also increases the risk of colorectal, ovarian, and other cancers.

Endometrial cancers occur most frequently in high-income countries, with Europe ranking second among continents in the rates of both incidence and mortality in 2020 **(Figure 4)**. In 2022, approximately 130,051 women in Europe were diagnosed with endometrial cancer, with 29,963 associated fatalities. Data from 2022 show that endometrial cancer's incidence is highest in central europe and mortality is highest in central and eastern europe **(Figures 5–6)**. However, the outlook for women diagnosed with endometrial cancer in Europe is relatively good, with nearly 80–85% surviving five years after diagnosis [(5,7,19)].

For more detailed information on the causes, diagnosis, and treatment of endometrial cancer, refer to the fact sheet developed by ENGAGe, which covers each of the gynaecological cancers.

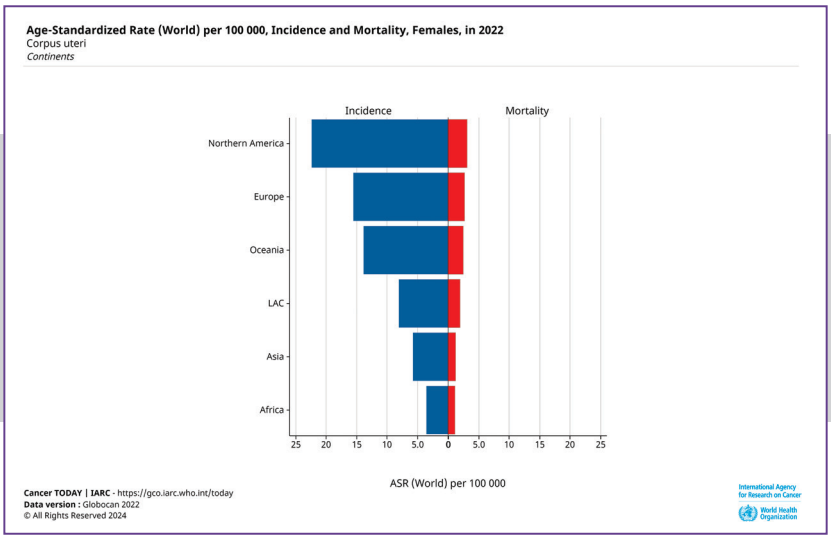
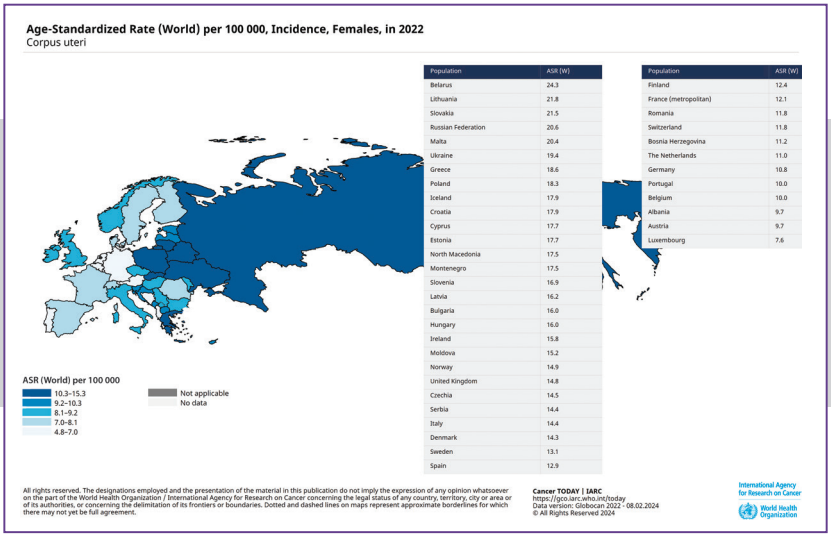


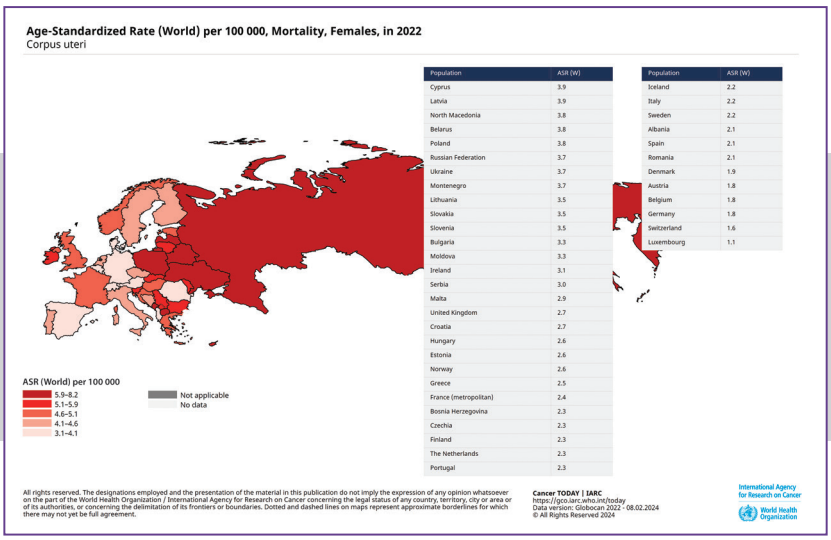
Figure 4: *Incidence and mortality rates of endometrial cancer by continent in women aged 0-85 in 2022, according to the World Health Organization (WHO) International Agency for Research on Cancer*



Population	ASR (W)
Belarus	24.3
Lithuania	21.8
Slovakia	21.5
Russian Federation	20.6
Malta	20.4
Ukraine	19.4
Greece	18.6
Poland	18.3
Iceland	17.9
Croatia	17.9
Cyprus	17.7
Estonia	17.7
North Macedonia	17.5
Montenegro	17.5
Slovenia	16.9
Latvia	16.2
Bulgaria	16.0
Hungary	16.0
Ireland	15.8
Moldova	15.2
Norway	14.9
United Kingdom	14.8
Czechia	14.5
Serbia	14.4
Italy	14.4
Denmark	14.3
Sweden	13.1
Spain	12.9

Population	ASR (W)
Finland	12.4
France (metropolitan)	12.1
Romania	11.8
Switzerland	11.8
Bosnia Herzegovina	11.2
The Netherlands	11.0
Germany	10.8
Portugal	10.0
Belgium	10.0
Albania	9.7
Austria	9.7
Luxembourg	7.6

Figure 5: *Estimated incidence rates for endometrial cancer in Europe in 2022*



Population	ASR (W)
Cyprus	3.9
Latvia	3.9
North Macedonia	3.8
Belarus	3.8
Poland	3.8
Russian Federation	3.7
Ukraine	3.7
Montenegro	3.7
Lithuania	3.5
Slovakia	3.5
Slovenia	3.5
Bulgaria	3.3
Moldova	3.3
Ireland	3.1
Serbia	3.0
Malta	2.9
United Kingdom	2.7
Croatia	2.7
Hungary	2.6
Estonia	2.6
Norway	2.6
Greece	2.5
France (metropolitan)	2.4
Bosnia Herzegovina	2.3
Czechia	2.3
Finland	2.3
The Netherlands	2.3
Portugal	2.3

Population	ASR (W)
Iceland	2.2
Italy	2.2
Sweden	2.2
Albania	2.1
Spain	2.1
Romania	2.1
Denmark	1.9
Austria	1.8
Belgium	1.8
Germany	1.8
Switzerland	1.6
Luxembourg	1.1

Figure 6: *Estimated Mortality Rates for endometrial Cancer in Europe in 2022*

Cervical cancer

The cervix is the lower part of the womb (uterus), extending into the upper part of the vagina.

Cervical cancer is the second most common cancer among women aged 15–44 [3]. The greatest incidence is observed in Central and Eastern Europe, where women have more than twice the risk of developing cervical cancer and more than three times the risk of dying from the disease compared with their Western European counterparts **(Figure 7)** [4,6].

According to the European Commission and the European Network of Cancer Registries, approximately 30,447 women were diagnosed with cervical cancer in 2020, with approximately 13,437 associated fatalities. Among European women of all ages, cervical cancer ranks as the eleventh most common cancer, with a lifetime risk of 1 in 111 [1,2].

Europe ranks fourth in incidence and fifth in mortality worldwide for cervical cancer, compared with other continents **(Figure 8)** [5]. On average, more than 60% of women in Europe survive five years after a cervical cancer diagnosis [1]. However, survival varies, with lower rates in Bulgaria, Latvia, Malta, and Poland (below 60%) and higher rates in Austria, Belgium, Croatia, Denmark, Finland, the Netherlands, Slovenia and Sweden. around 70%) **(Figure 9)** [1,6].

Infection with human papillomavirus (HPV), particularly high-risk types such as HPV16 and HPV18, is the primary risk factor for cervical cancer. HPV vaccination and screening methods have proven highly effective in preventing cervical cancer. Furthermore, all initiatives for quitting smoking should be intensified to improve women's health, including the risk for developing cervical dysplasia and cervical cancer.

In 2020, for the first time in the history of the World Health Organisation (WHO), the World Health Assembly (WHA) adopted a comprehensive global strategy to eliminate cervical cancer. The unanimously agreed upon resolution WHA 73.2 urges all WHO member states — every country in the world — to implement nationally the WHO blueprint of the global cervical cancer strategy and to adopt its associated goals and targets.

For more detailed information on the causes, diagnosis, and treatment of cervical cancer, refer to the fact sheet developed by ENGAGe, which covers each of the gynaecological cancers.

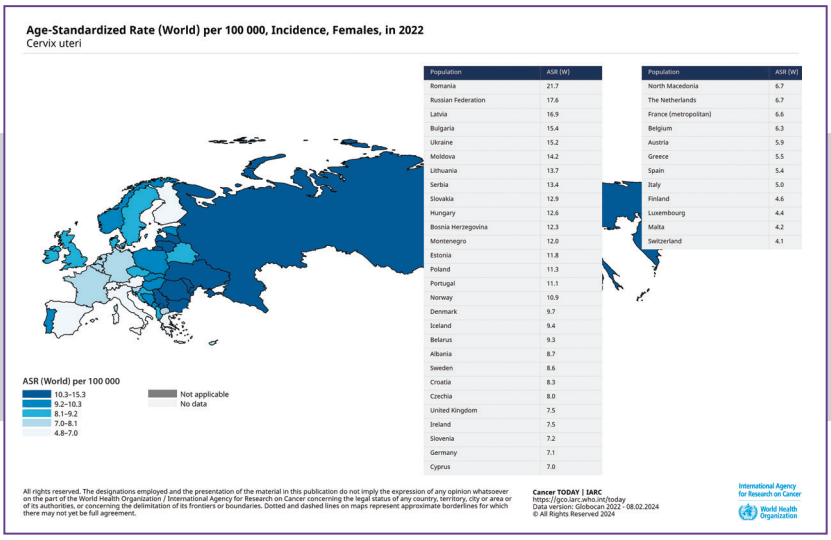


Figure 7: *Estimated incidence rates for cervical cancer in Europe in 2022*

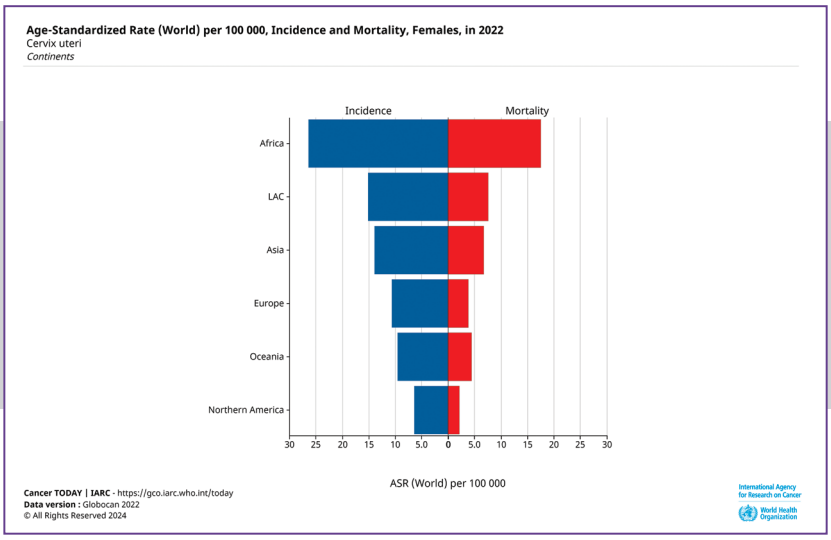


Figure 8: *Incidence and mortality rates of cervical cancer by continent in women aged 0-85 in 2022, according to the World Health Organization (WHO) International Agency for Research on Cancer*

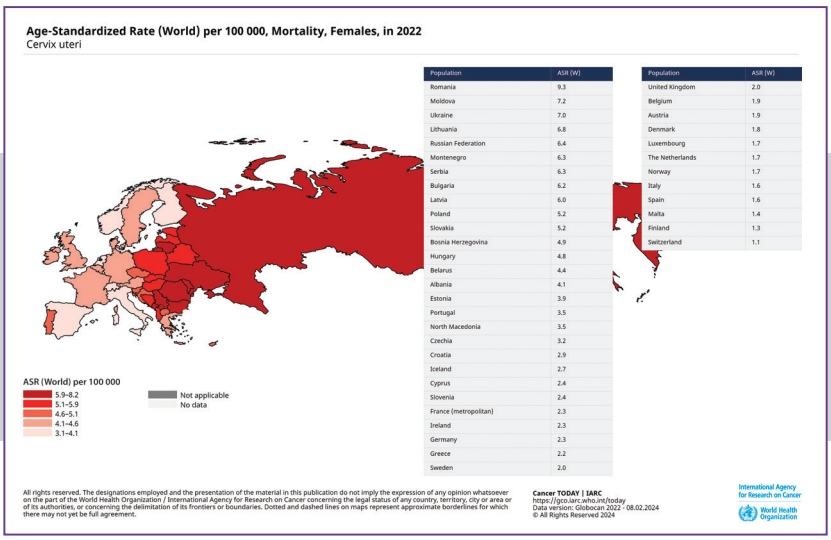


Figure 9: *Estimated Mortality Rates for cervical Cancer in Europe in 2022*

Vulvar cancer

The vulva consists of several external organs, including the labia majora (outer lips), labia minora (inner lips), and clitoris, as well as the opening of the vagina and the urethra (the tube leading from the bladder).

Vulvar cancer is relatively rare, accounting for approximately 4% of all genital cancers in women [(10)]. It is crucial to distinguish vulvar cancer from vaginal cancer, as both are distinct yet related to the female genital area.

Historically viewed as a cancer affecting post-menopausal women, vulvar cancer has seen a shift in age of onset. Recent years have marked a decline in the mean age of diagnosis, largely due to an uptick in HPV infections globally. Women over 65 years old remain the most vulnerable to developing vulvar cancer. However, an increase in cases among younger women is becoming evident, potentially linked to rising rates of HPV infection and tobacco use [(11,12)].

In 2022, Europe ranks second in vulvar cancer incidence and mortality compared with other continents **(Figure 10)** [(5)]. In 2020, the Global Cancer Observatory and the International Agency for Research on Cancer reported 16,506 new cases of primary vulvar cancer in Europe, with 6,503 associated fatalities [(5,7)]. Geographically, the risk varies across Europe, with higher incidence rates in Eastern and Northern countries compared with Western and Southern in 2022 **(Figure 11)**.

A 2017 epidemiological study spanning 13 high-income countries revealed a notable 14% rise in vulvar cancer incidence overall. This increase, however, was not uniform across all age groups. Women under 60 experienced a 38% increase in incidence, while no significant change was observed in women over 60 [(13)].

The prognosis of vulvar cancer varies by stage. For early-stage diagnoses, more than 80% of women are expected to survive beyond five years. However, when analysing survival for all disease stages together, almost 60% of patients with vulvar cancer are expected to remain alive five years after diagnosis **(Figure 12)** [(14)].

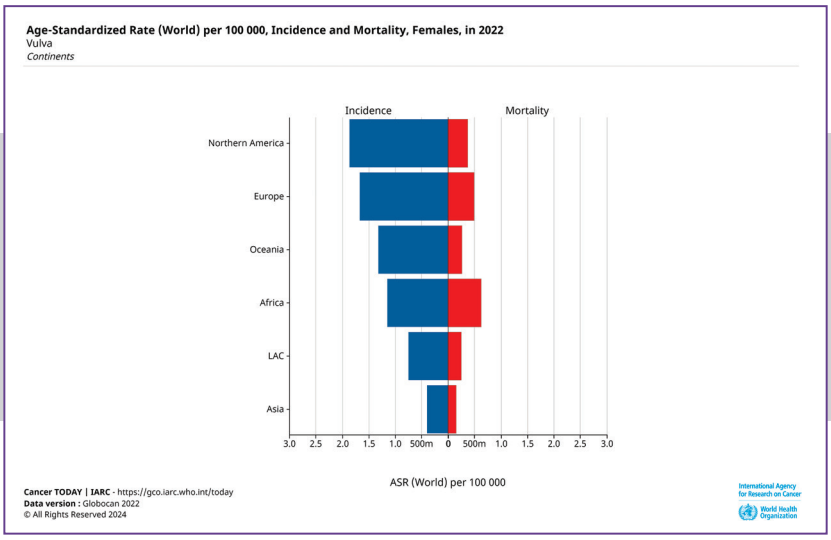


Figure 10: *Incidence and mortality rates of vulvar cancer by continent in women aged 0-85 in 2022, according to the World Health Organization (WHO) International Agency for Research on Cancer*

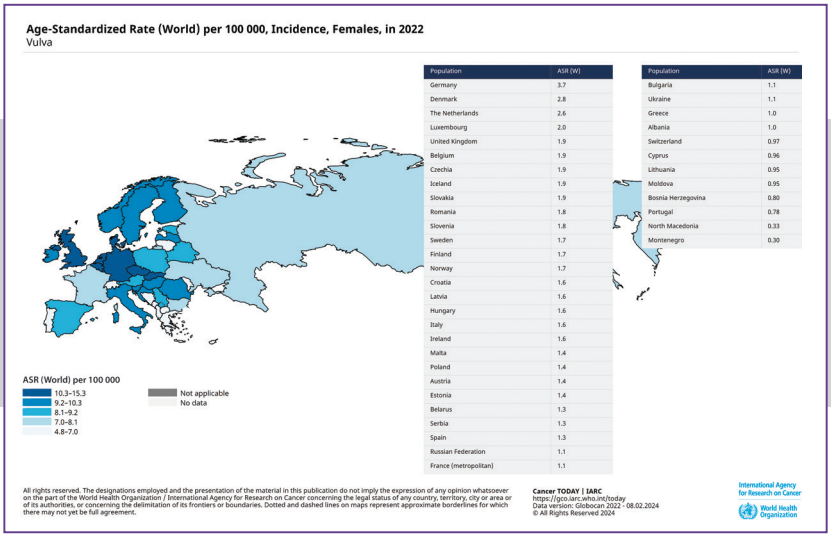


Figure 11: *Estimated incidence rates for vulvar cancer in Europe in 2022*

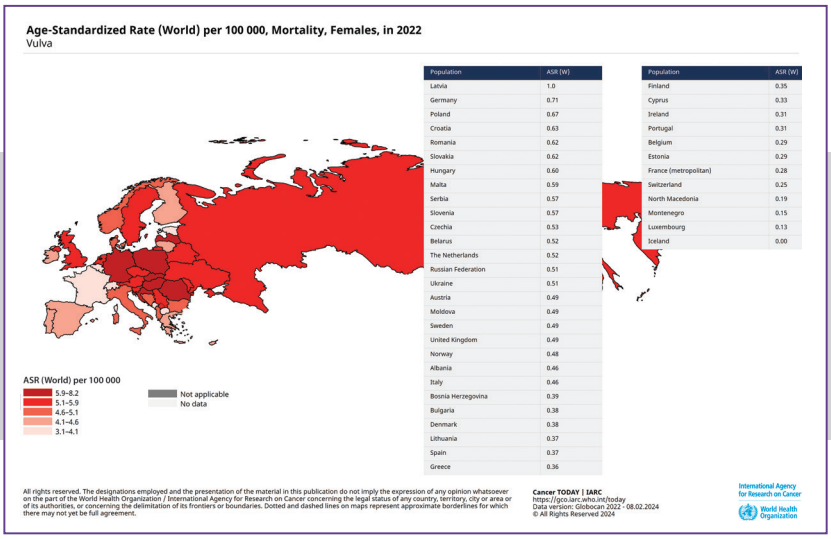


Figure 12: *Estimated Mortality Rates for vulvar Cancer in Europe in 2022*

Vaginal cancer

The vagina is a muscular passage linking the cervix (neck of the uterus) to the vulva (external genitals). Primary vaginal cancer, a rare type of the disease that develops in the vagina, accounts for less than 1–2% of all genital cancers in women [15].

Vaginal cancer is often linked to the human papillomavirus (HPV) and other risk factors such as smoking, as well as to immunosuppression (decreased immunity states that can be attributed to certain diseases or drug-induced). This type of cancer is typically more common among older, postmenopausal women, but its incidence is rising in younger women due to HPV infections [15].

The most frequent histological subtype of vaginal cancer is squamous cell carcinoma, followed by adenocarcinoma. Melanomas, lymphomas, and sarcomas are more rare. The cancer usually starts at the top part of the vagina, with its spread depending on location [15].

In 2022, according to the Global Cancer Observatory and the International Agency for Research on Cancer, Europe ranked fifth in vaginal cancer incidence and fourth in mortality compared with other continents **(Figure 13)** [5]. That same year, 2,947 women in Europe were diagnosed with the disease, with 1,267 associated fatalities [5,7]. In Europe, the incidence and mortality of this type of cancer varies, being more common in Northern and Eastern Europe and less common in Southern Europe, possibly due to differences in the number of HPV infections and the availability of cervical screening programs **(Figures 14-15)** [6].

Early diagnosis is crucial for survival from vaginal cancer, with a survival rate of 95% when detected early but significantly lower at advanced stages [15]. Treatment often involves radiation therapy and brachytherapy, which are crucial for controlling the cancer, improving survival, and reducing side effects. Treatment should be individualized for each tumour.

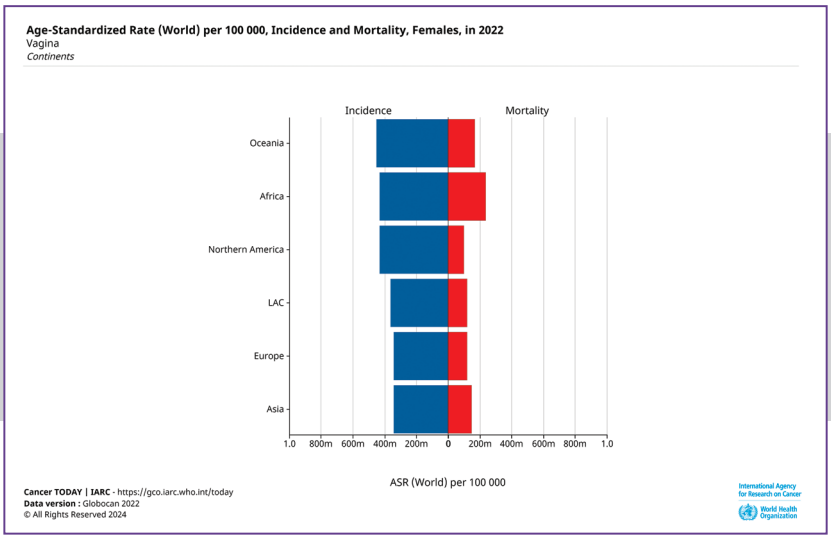
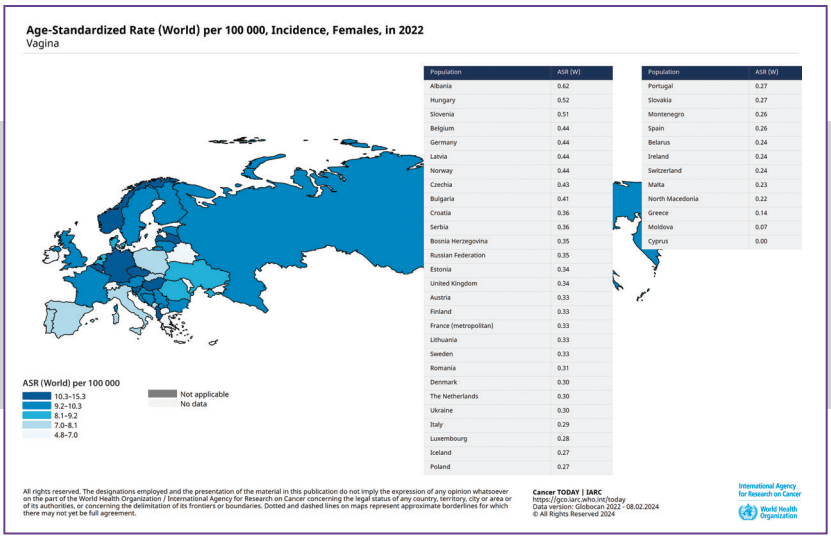


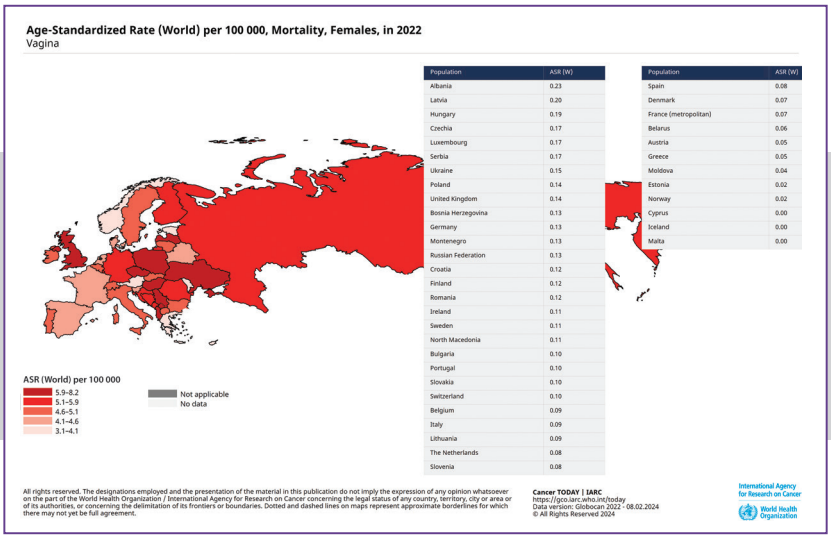
Figure 13: *Incidence and mortality rates of vaginal cancer by continent in women aged 0-85 in 2022, according to the World Health Organization (WHO) International Agency for Research on Cancer*



Population	ASR (W)
Albania	0.62
Hungary	0.52
Slovenia	0.51
Belgium	0.44
Germany	0.44
Latvia	0.44
Norway	0.44
Czechia	0.43
Bulgaria	0.41
Croatia	0.36
Serbia	0.36
Bosnia Herzegovina	0.35
Russian Federation	0.35
Estonia	0.34
United Kingdom	0.34
Austria	0.33
Finland	0.33
France (metropolitan)	0.33
Lithuania	0.33
Sweden	0.33
Romania	0.31
Denmark	0.30
The Netherlands	0.30
Ukraine	0.30
Italy	0.29
Luxembourg	0.28
Iceland	0.27
Poland	0.27

Population	ASR (W)
Portugal	0.27
Slovakia	0.27
Montenegro	0.26
Spain	0.26
Belarus	0.24
Ireland	0.24
Switzerland	0.24
Malta	0.23
North Macedonia	0.22
Greece	0.14
Moldova	0.07
Cyprus	0.00

Figure 14: *Estimated incidence rates for vaginal cancer in Europe in 2022*



Population	ASR (W)
Albania	0.23
Latvia	0.20
Hungary	0.19
Czechia	0.17
Luxembourg	0.17
Serbia	0.17
Ukraine	0.15
Poland	0.14
United Kingdom	0.14
Bosnia Herzegovina	0.13
Germany	0.13
Montenegro	0.13
Russian Federation	0.13
Croatia	0.12
Finland	0.12
Romania	0.12
Ireland	0.11
Sweden	0.11
North Macedonia	0.11
Bulgaria	0.10
Portugal	0.10
Slovakia	0.10
Switzerland	0.10
Belgium	0.09
Italy	0.09
Lithuania	0.09
The Netherlands	0.08
Slovenia	0.08

Population	ASR (W)
Spain	0.08
Denmark	0.07
France (metropolitan)	0.07
Belarus	0.06
Austria	0.05
Greece	0.05
Moldova	0.04
Estonia	0.02
Norway	0.02
Cyprus	0.00
Iceland	0.00
Malta	0.00

Figure 15: *Estimated Mortality Rates for vaginal Cancer in Europe in 2022*

Breast cancer

Breast cancer, the most frequently diagnosed cancer in Europe, arises primarily in the breast's lobules (milk-producing glands) or ducts (channels for transporting milk to the nipples). Notably, more than 80% of breast cancers now originate in the ducts. Less commonly, breast cancer can begin in stromal tissue, which includes the fatty and fibrous connective tissues of the breast.

Europe ranks third in the world in terms of incidence and in terms of mortality for breast cancer **(Figure 16)**. In 2020, breast cancer accounted for 13.3% of all new cancer cases diagnosed and 28.7% of all new cancer in women in EU-27 countries, making it the most frequently occurring cancer. That same year, breast cancer accounted for an estimated 531,086 new cases and 141,765 associated fatalities, according to the European Commission and the European Network of Cancer Registries [5,7,20].

This malignancy predominantly affects women over 50 and more commonly appears in Northern and Western Europe **(Figure 17)**. Despite breast cancer's prevalence, the survival rate has significantly improved, with more than 80% of women expected to survive five years after diagnosis, especially in Western Europe. This improvement is attributed to enhanced screening, early detection, and advanced treatments. Screening programs in Europe led to a 25–30% reduction in breast cancer mortality among women aged 50–74 [21]. However, survival rates vary across Europe, reflecting differences in healthcare quality and access **(Figure 18)**.

Current trends show a rising incidence of breast cancer, influenced by lifestyle factors like obesity and physical inactivity, but a declining mortality rate due to effective treatments and early detection strategies [22].

ENGAGe does not focus on breast cancer in the scope of its activities.

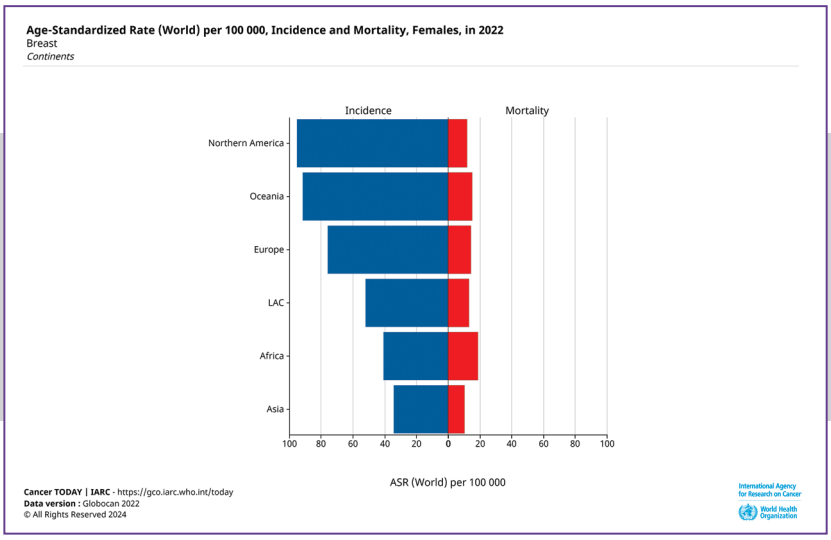
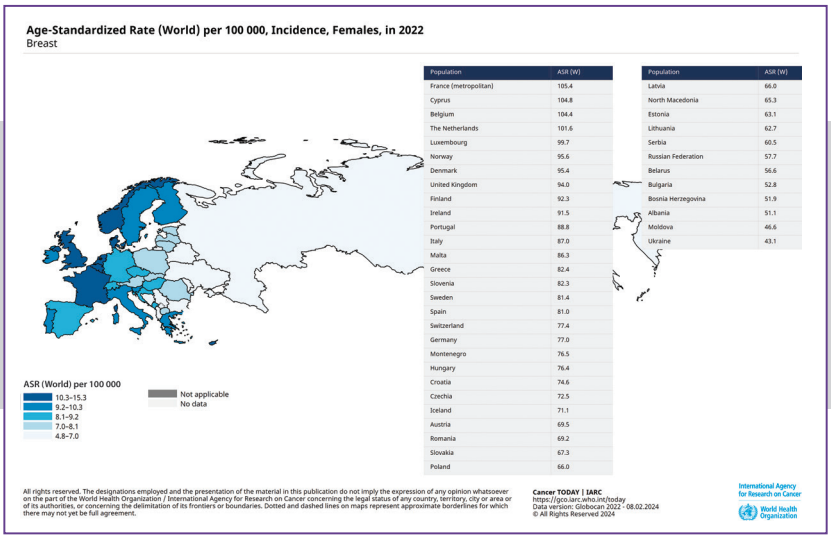


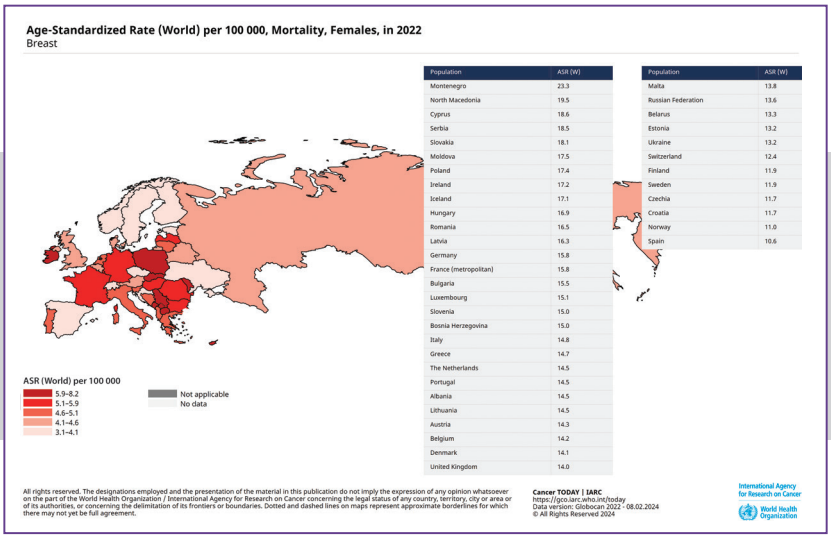
Figure 16: *Incidence and mortality rates of Breast cancer by continent in women aged 0-85 in 2022, according to the World Health Organization (WHO) International Agency for Research on Cancer*



Population	ASR (W)
France (metropolitan)	105.4
Cyprus	104.8
Belgium	104.4
The Netherlands	101.6
Luxembourg	99.7
Norway	95.6
Denmark	95.4
United Kingdom	94.0
Finland	92.3
Ireland	91.5
Portugal	88.8
Italy	87.0
Malta	86.3
Greece	82.4
Slovenia	82.3
Sweden	81.4
Spain	81.0
Switzerland	77.4
Germany	77.0
Montenegro	76.5
Hungary	76.4
Croatia	74.6
Czechia	72.5
Iceland	71.1
Austria	69.5
Romania	69.2
Slovakia	67.3
Poland	66.0

Population	ASR (W)
Latvia	66.0
North Macedonia	65.3
Estonia	63.1
Lithuania	62.7
Serbia	60.5
Russian Federation	57.7
Belarus	56.6
Bulgaria	52.8
Bosnia Herzegovina	51.9
Albania	51.1
Moldova	46.6
Ukraine	43.1

Figure 17: *Estimated incidence rates for Breast cancer in Europe in 2022*



Population	ASR (W)
Montenegro	23.3
North Macedonia	19.5
Cyprus	18.6
Serbia	18.5
Slovakia	18.1
Moldova	17.5
Poland	17.4
Ireland	17.2
Iceland	17.1
Hungary	16.9
Romania	16.5
Latvia	16.3
Germany	15.8
France (metropolitan)	15.8
Bulgaria	15.5
Luxembourg	15.1
Slovenia	15.0
Bosnia Herzegovina	15.0
Italy	14.8
Greece	14.7
The Netherlands	14.5
Portugal	14.5
Albania	14.5
Lithuania	14.5
Austria	14.3
Belgium	14.2
Denmark	14.1
United Kingdom	14.0

Population	ASR (W)
Malta	13.8
Russian Federation	13.6
Belarus	13.3
Estonia	13.2
Ukraine	13.2
Switzerland	12.4
Finland	11.9
Sweden	11.9
Czechia	11.7
Croatia	11.7
Norway	11.0
Spain	10.6

Figure 18: *Estimated Mortality Rates for Breast Cancer in Europe in 2022*

Family risk

All cancers, including gynaecological cancers, are caused by damages or changes (mutations) in our genes. Comprised of DNA, genes are present in every cell of our body and dictate the function of cells, including their growth and death. Genes act like on/off switches inside our cells. When a gene undergoes a mutation, the instructions it provides to the cell can become altered, leading to abnormal cellular development.

Mutations occur frequently in our cells. Each time a cell divides, there's a risk of an error in copying its DNA. Usually, our cells can detect and repair these errors, but sometimes they fail, passing on the mutations to new cells. Those cells with mutations due to DNA damage can become cancerous. Aging, environment, and lifestyle can alter our body's repair mechanisms, resulting in the accumulation of mutations and increasing the risk of cancer [(23)].

Most gynaecological and other cancers are sporadic; that is, they occur by chance, influenced by both internal and external factors. However, a minority of women are more likely to develop cancer, including gynaecological cancers, because they have a familial or hereditary risk.

Gynaecological cancers are more frequently linked to genetic factors than are other types of cancer [(24)]. Of the families of genetic diseases, those most frequently encountered include hereditary breast and ovarian cancer, Lynch syndrome, Peutz-Jeghers syndrome, and Cowden syndrome.

Familial cancers

Cancer is familial when more cases than expected occur in a family but there is no clear pattern of inheritance and the disease occurs at around the average age of diagnosis. Familial cancers are probably caused by a combination of several hereditary genes and shared lifestyles.

Women in families with BRCA mutations are more likely to develop breast cancer and/or ovarian cancer if they have a mother, sister, or daughter with the disease, with the risk increasing with the number of affected relatives. However, even when several relatives are affected, most women will not experience familial breast and or ovarian cancer [(25)].

Hereditary cancers

Some cancers are caused by genetic changes we are born with, inherited from our parents. **Individuals with hereditary genetic mutations have a higher risk of developing cancer, though it is not guaranteed.** Hereditary cancer tends to occur more frequently and at a younger age compared with other types of cancer.

Factors suggesting that a woman may be at risk of hereditary cancer include:

- several cancers of the same type on the same side of the family;
- cancers occurring at young ages (usually less than 50 years);
- cancers known to be associated with an inherited syndrome, including breast, ovarian uterine, bowel, and stomach cancers; and
- several primary cancers (e.g., breast cancer occurring in both breasts at the same time).

About 5–10% of all cancers are inherited [26].

There are several hereditary cancer syndromes associated with gynaecologic malignancies. The most common include hereditary breast and ovarian cancer, as well as Lynch, Peutz-Jeghers, Cowden, and Li-Fraumeni syndromes. These syndromes carry varying risks of developing breast, ovarian, and uterine malignancies [27].

TWO TYPES OF GENETIC MUTATION ARE KNOWN TO INCREASE THE RISK OF INHERITED GYNAECOLOGICAL CANCERS:

- **Hereditary breast and ovarian cancer syndrome** (HBOC) is the result of mutations in either the BRCA1 or BRCA2 genes. In cases of BRCA1 mutation, there is a cumulative breast cancer risk of 72% up to age 80 and a cumulative ovarian cancer risk of 44% up to age 80. In instances of BRCA2 mutation, the cumulative risks are 69% for breast cancer and 17% for ovarian cancer [28].
- **Hereditary non-polyposis colorectal cancer** (HNPCC; also known as Lynch syndrome) is caused by a mutation in at least one of five genes: MLH1, MSH2, MSH6, PMS1, and PMS2. Women with Lynch syndrome may have a lifetime risk of up to 60% for endometrial cancer and up to 20% for ovarian cancer, as well as a high risk for colon cancer, depending on their underlying genetic mutations [29].

The decision to undergo genetic testing is never straightforward and requires professional consultation and risk evaluation. **Genetic testing can identify the risk for each woman in an affected family**; however, a positive test result may either reassure a woman or increase her anxiety. In cases of positive testing, tailored screening and risk-reducing interventions may be available.

For more information on genetic testing please consult the brochure on Genetic testing for patients with cancer predisposing genes.

CONCLUSION

This brochure summarizes the most recent epidemiologic data on gynaecological cancer. When comparing the data with that included in the 2018 ENGAGe brochure, one can see that significant progress has been made based on the activities of the European Network for Gynaecological Oncological Trial groups (ENGOT) and others. Despite this progress, however, we still identify areas for improvement.

Cervical cancer can be fully eradicated by following WHO's 90-70-90 recommendation, which calls for 90% of girls being fully vaccinated against HPV by age 15, 70% of women being screened with a high-performance test by age 35 and again by age 45, and 90% of women with pre-cancerous lesions being treated and 90% of women with invasive cancer being managed (30). Prevention, detection, and adequate treatment are the keys to achieving the highest rate of cancer patient survival.

Informed and educated patients know how to ask the right questions and, together with their clinician, can agree on the most appropriate courses of treatment. At ENGAGe, we want to improve the level of European patients' access to information, education, and innovation. This brochure is one tool to help reach our goals.

References

1. Bettio M, Dimitrova N, Florensa Molist M, Randi G, Giusti F, Martos Jimenez M, et al. Cervical cancer burden in EU-27. European Commission; 2021.
2. Bruni L, Albero G, Serrano B, Mena M, Collado JJ, Gómez D, et al. ICO/IARC Information Centre on HPV and Cancer (HPV Information Centre). Human papillomavirus and related diseases in the world. Summary report; 2023 Mar 10.
3. Wojtyla C, Janik-Koncewicz K, La Vecchia C. Cervical cancer mortality in young adult European women. Eur J Cancer. 2020 Feb;126:56–64.
4. Wojtyla C, Ciebiera M, Kowalczyk D, Panek G. Cervical cancer mortality in East-Central European countries. Int J Environ Res Public Health. 2020 Jul;17(13):4639.
5. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin. 2021 May;71(3):209–49.
6. Randi G, Zaro F, Carvalho RN, Martos C, Dimitrova N, Dyba T, et al. The European Cancer Information System (ECIS) web application. Technical report; 2018 Sep.
7. International Agency for Research on Cancer. Cancer today [Internet]. [cited 2024 April 27]. Available from: http://gco.iarc.fr/today/home
8. Wojtyła C, Bertuccio P, Giermaziak W, Santucci C, Odone A, Ciebiera M, et al. European trends in ovarian cancer mortality, 1990–2020 and predictions to 2025. Eur J Cancer [Internet]. 2023 Nov 1 [cited 2023 Nov 27];194. Available from: https://www.ejcancer.com/article/S0959-8049(23)00652-4/fulltext
9. Bahena-González A, Toledo-Leyva A, Gallardo-Rincón D. PARP inhibitors in ovarian cancer: Evidence for maintenance and treatment strategies. Chin Clin Oncol. 2020 Aug;9(4):51.
10. Olawaiye AB, Cuello MA, Rogers LJ. Cancer of the vulva: 2021 update. Int J Gynecol Obstet. 2021 Oct;155(S1):7–18.
11. Faber MT, Sand FL, Albieri V, Norrild B, Kjaer SK, Verdoodt F. Prevalence and type distribution of human papillomavirus in squamous cell carcinoma and intraepithelial neoplasia of the vulva. Int J Cancer. 2017 Sep 15;141(6):1161–9.
12. Xiao X, Meng YB, Bai P, Zou J, Zhang Y, Nguyen TMB, et al. Vulvar cancer in China: Epidemiological features and risk analysis. J Cancer. 2017;8(15):2950–8.
13. Kang YJ, Smith M, Barlow E, Coffey K, Hacker N, Canfell K. Vulvar cancer in high-income countries: Increasing burden of disease. Int J Cancer. 2017 Dec 1;141(11):2174–86.
14. Iacoponi S, Zapardiel I, on behalf of VULCAN Study Collaborative Group. European nationality influence in the management of squamous cell vulvar cancer. Gynecol Obstet Invest. 2017;82(4):349–54.
15. Jhingran A. Updates in the treatment of vaginal cancer. Int J Gynecol Cancer. 2022 Mar;32(3):344–51.
16. Morice P, Leary A, Creutzberg C, Abu-Rustum N, Darai E. Endometrial cancer. Lancet Lond Engl. 2016 Mar 12;387(10023):1094–108.
17. Berek JS, Matias-Guiu X, Creutzberg C, Fotopoulou C, Gaffney D, Kehoe S, et al. FIGO staging of endometrial cancer: 2023. Int J Gynecol Obstet. 2023 Aug;162(2):383–94.
18. Concin N, Matias-Guiu X, Vergote I, Cibula D, Mirza MR, Marnitz S, et al. ESGO/ESTRO/ESP guidelines for the management of patients with endometrial carcinoma. Int J Gynecol Cancer. 2021 Jan;31(1):12–39.
19. Cao S-Y, Fan Y, Zhang Y-F, Ruan J-Y, Mu Y, Li J-K. Recurrence and survival of patients with stage III endometrial cancer after radical surgery followed by adjuvant chemo- or chemoradiotherapy: A systematic review and meta-analysis. BMC Cancer. 2023 Jan 9;23:31.
20. European Cancer Information System. Cancer burden statistics and trends across Europe [Internet]. [cited 2023 Dec 21]. Available from: https://ecis.jrc.ec.europa.eu/
21. Peintinger F. National breast screening programs across Europe. Breast Care. 2019 Dec;14(6):354–8.
22. OECD, European Union. Health at a glance: Europe 2022: State of health in the EU Cycle [Internet]. OECD; 2022 [cited 2023 Dec 23]. Available from: https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-europe-2022_507433b0-en
23. DeVita VT, Lawrence TS, Rosenberg SA, editors. Devita, Hellman, and Rosenberg's cancer: Principles and practice of oncology. Twelfth edition. Philadelphia: Wolters Kluwer; 2023.
24. Ogawa C, Hirasawa A, Ida N, Nakamura K, Masuyama H. Hereditary gynecologic tumors and precision cancer medicine. J Obstet Gynaecol Res. 2022 May;48(5):1076–90.
25. Bach C. Genetic testing for familial gynecologic cancer (endometrial and ovarian cancers) [Internet]. OncoLink; 2023 [cited 2023 Dec 23]. Available from: https://www.oncolink.org/risk-and-prevention/genetics-family-history/genetic-testing-for-familial-gynecologic-cancer-endometrial-and-ovarian-cancers
26. Hart SN, Polley EC, Yussuf A, Yadav S, Goldgar DE, Hu C, et al. Mutation prevalence tables for hereditary cancer derived from multigene panel testing. Hum Mutat. 2020 Aug;41(8):e1–6.
27. Wade KS, Estes JM, Kline RC. Genetics and the gynecologic patient. Ochsner J. 2020;20(4):446–51.
28. Kuchenbaecker KB, Hopper JL, Barnes DR, Phillips KA, Mooij TM, Roos-Blom MJ, et al. Risks of breast, ovarian, and contralateral breast cancer for BRCA1 and BRCA2 mutation carriers. JAMA. 2017 Jun 20;317(23):2402–16.
29. Amirthanayagam A, Crawford R. Genetics in gynae-oncology: Diagnostic and therapeutic implications. Obstet Gynaecol Reprod Med. 2022 Feb 1;32(2):1–6.
30. World Health Organization. Cervical cancer elimination initiative [Internet]. [cited 2020]. Available from: https://www.who.int/initiatives/cervical-cancer-elimination-initiative#cms

ENGAGe
ESGO European Network of Gynaecological Cancer Advocacy Groups

ENGAGe expresses sincere gratitude to the author of this brochure, Dr. Houssein El Hajj (France), to Kim Hulscher (the Netherlands) for her patient perspective, and to Prof. Jalid Sehouli for reviewing this brochure.

ENGAGe would also like to thank the ENGAGe Executive Group members for their constant availability and cooperation.

Contact information of ENGAGe

Webpage: https://engage.esgo.org/

Email: engage@esgo.org

Facebook: https://www.facebook.com/engage.esgo

ENGAGe recommends contacting your local patient association!

ENGAGe

ESGO | European Network of Gynaecological Cancer Advocacy Groups