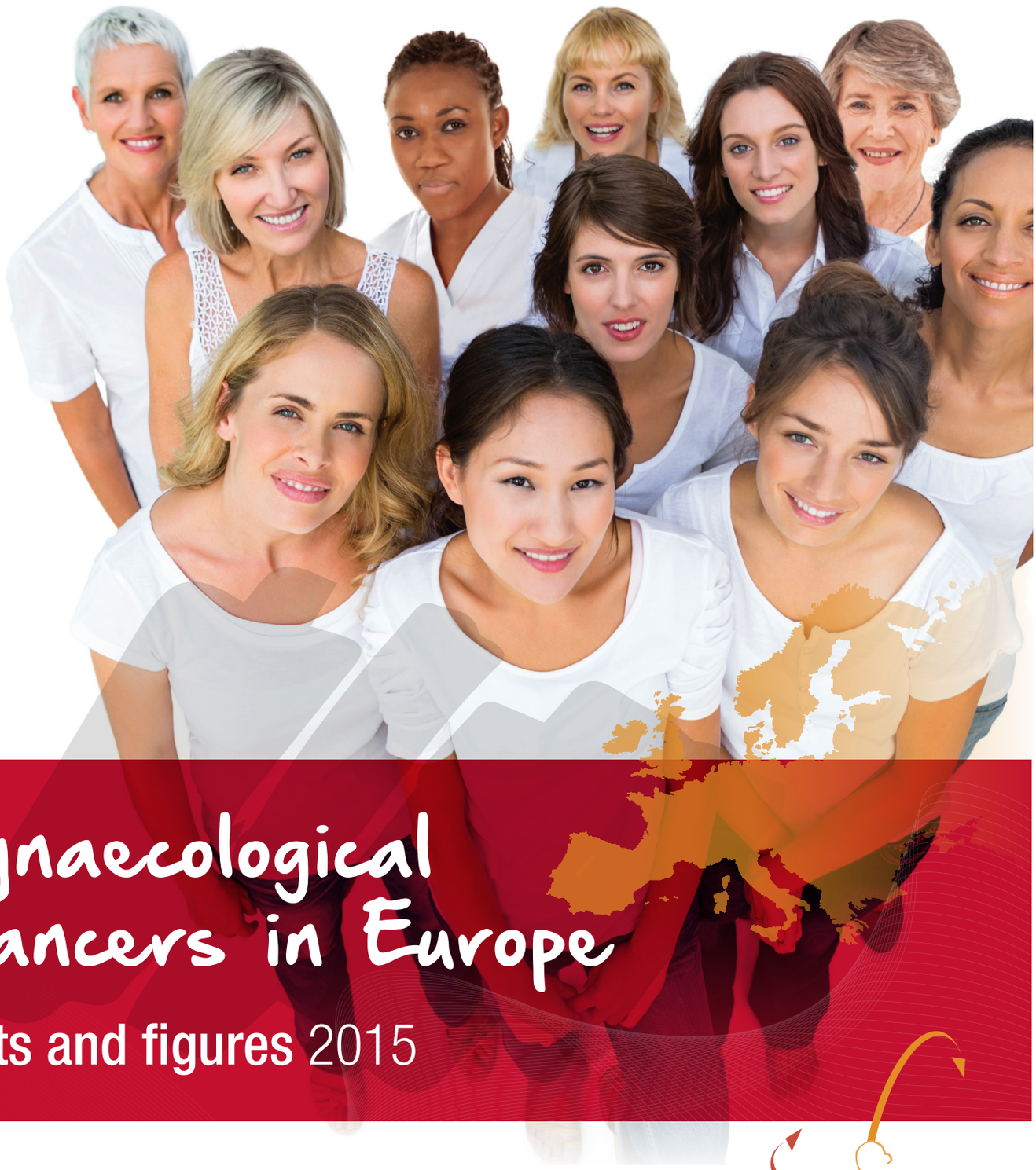
ESGO
European Society of Gynaecological Oncology

ENGAGeO
ESGO | European Network of Gynaecological Cancer Advocacy Groups



Gynaecological Cancers in Europe

Facts and figures 2015

The European Voice of Gynaecological Oncology

Contents

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LET'S BREAK THE SILENCE ABOUT WOMEN'S CANCERS

Ovarian, uterine, cervix and other gynaecological cancers are among the most common cancers to affect women, but collectively attract less attention than they deserve from the public and policy makers. Women themselves may be unaware of the sometimes vague symptoms or may be too embarrassed to consult a doctor, and there remains a stigma associated with these diagnoses in some quarters. This reticence needs to be overcome and a more positive message developed to improve the prevention, screening, treatment and care of gynaecological cancers so that women throughout Europe have the best chance of survival and quality of life.

Facing the challenge together

Gynaecological cancers include common cancers of the womb (uterus), ovary, and cervix as well as rare cancers affecting the vulva, vagina and fallopian tubes. In some countries, care of gynaecological cancer 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 women living with gynaecological cancers to obtain accurate, reliable, and timely information about their disease, to understand treatment options and to have access to the best possible care.

This is the third revised and fully updated edition of a report first published in 2011 to mark ESGO's first Patient Seminar. Since then, 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.

Closing the gap

Much has been achieved in some cancers over the past decade. However, the rarer cancers are often left behind, receiving little attention in basic science, research, industry and health policy. There remains a significant gap between what we know and what we do across the world and in Europe, especially in the less well-recognised 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 cancer team. Treatment decisions will be influenced by a woman's age and the stage, grade and increasingly the genetics of her cancer. There are also continuing inequalities both between and within European countries in cancer risk, detection and treatment.

If we are to improve outcomes in women's gynaecological cancers in Europe, we must ensure that the proven benefits of cervical cancer screening and HPV vaccination are extended to all countries, and that every woman with ovarian cancer is referred to a centre specialising in the treatment of this disease. On the broader public health front, we must also raise awareness that reducing the prevalence of obesity among women will not only improve their general health but also lower their risk of uterine and other cancers. Reliable public and patient information and education are often lacking, especially in non-English language countries. Patients and families need easy access to accurate and understandable information in all languages, and this needs to be presented in a variety of media channels. Myths and misconceptions must be clarified to dispel stigma that is sometimes associated with gynaecological cancers.

Education and resources

Molecular characterisation of tumours has led to the broad categories such as ovarian and endometrial (womb) cancers being broken down into sub-types with different treatments and outcomes. These and other recent developments emphasise the importance of specialised training and certification programmes for professionals and institutions caring for gynaecological cancer patients. There is increasing evidence that the outcome of women's cancers is better when treatment is provided by specialised teams and in specialised hospitals that can offer a multidisciplinary approach that draws on both surgical and medical expertise.

High-quality care includes access to appropriate therapies, within centres with sufficient case volume and skills, radiotherapy equipment and trained medical and supporting professionals, as well as facilities for rehabilitation and long-term follow-up.

Coping and support systems should be accessible to all patients and families, and delivered by trained professionals such as specialist support nurses. Optimal psychosocial care should be available at all stages of the disease and during follow-up, whenever it is needed, within a reasonable distance from the patient's home.

Knowledge and awareness

Further research is required to better understand how to treat each gynaecological cancer, including use of targeted therapies with novel molecular drugs where available. The patient's role needs to be better understood, including involvement in clinical trials and current barriers to participation in research. Patient organisations have a unique knowledge about their disease, treatment and quality of life. These insights are of great value to researchers and policymakers when priorities need to be set, and through questionnaire studies there is an increasing evidence base to support these programmes.

The benefits of quitting tobacco use, as well as the importance of a healthy weight, diet and physical activity to maintain health and quality of life need to be better understood by patients, as well as by healthy individuals.

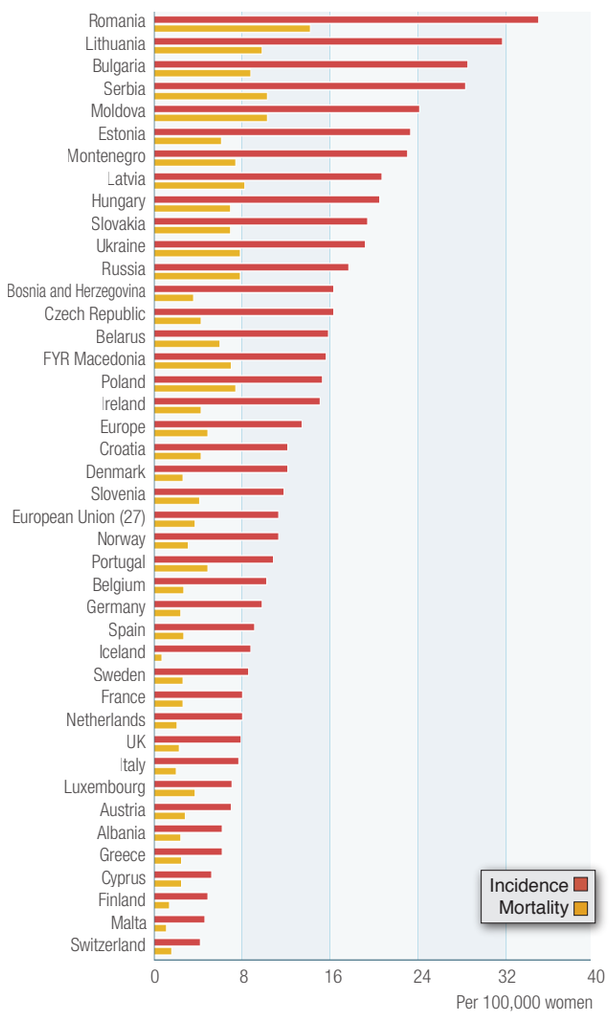
Patient advocacy and mobilising change

A shared advocacy agenda across gynaecological cancer patient groups will increase the attention of policy makers, help to reveal inequalities and give gynaecological cancers higher priority on the European health agenda. Joint action will also give patient groups the opportunity to synergise, to share best practice and to improve knowledge of advocacy in patient organisations across specific diseases. ESGO aims to support patients by providing a platform for dialogue and action on key issues concerning gynaecological cancers in Europe. We are, for example, aware that rare and uncommon gynaecological cancers do not always get the attention they need and that more research is needed in order to save lives. It is important for us to join forces with other research groups and rare cancer initiatives.

Cervical cancer

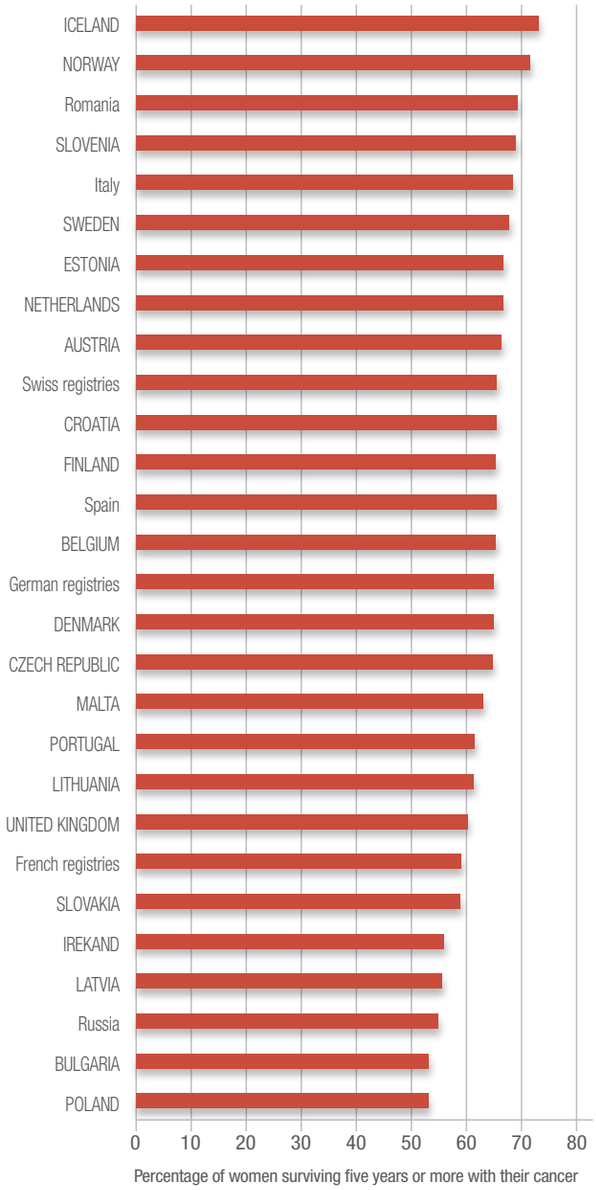
The cervix is the lower third of the womb (uterus), which extends down into the upper part of the vagina. In 2012, over 58,000 women in Europe were diagnosed with cervical cancer and around 24,000 women died of the disease.[1] While it is the fifth most common cancer among European women of all ages,[2] cervical cancer is the second most common cancer in women aged 15-39 years.[3] Rates are highest among women in the countries of Eastern Europe, who have over three times the risk of dying of cervical cancer of Western European women.[1]

Cervical cancer: estimated incidence and mortality, 2012[2]



On average over 60% women in Europe are alive five years after a diagnosis of cervical cancer.[4] Survival rates however vary, and are low in Poland, Bulgaria, Russia, Latvia, Ireland, Slovakia, France and the United Kingdom.[5]

Cervical cancer: five-year net survival[5]



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What causes cervical cancer?

Virtually all cervical cancers are caused by human papilloma virus (HPV) infection. HPV may cause a spectrum of precancerous changes known as cervical intraepthelial neoplasia (CIN) and a small proportion of these will develop into invasive cervical cancer. This process, from HPV infection to invasive cervical cancer, usually takes at least 10-15 years.

Cervical cancer-causing HPV types are nearly always transmitted following sexual contact with an infected person. Since women who have had several sexual partners are generally at higher risk of becoming infected with HPV, they also have a greater risk of developing cervical cancer. But it does not mean that a woman who develops cervical cancer has had several sexual partners. A woman who has only ever had one sexual partner can develop cervical cancer if she becomes infected by cancer-causing HPV.

Other factors that increase the likelihood of cervical cancer include:[6,7]

- Having several children
- Smoking
- Long-term use of oral contraceptives
- Other infections including herpes and chlamydia
- Immunosuppression; e.g. HIV or organ transplantation.

Can women protect themselves against cervical cancer?

HPV affects most women at some time in their lives. However, in 80% of cases the virus will clear spontaneously. Only women who have persistent infection with high-risk HPV types and additional risk factors such as immunodeficiency, smoking or genetic predisposition are likely to develop cervical cancer. Screening can reduce the risk of cervical cancer by up to 80% in women who participate.[8] Most European countries offer some form of cervical screening, but programmes may not identify or invite all eligible women. Women's participation in screening also varies within and between countries.[9] Immigrant populations may not be aware of these facilities, and in some cases there may be cultural issues reducing uptake. HPV vaccination is now offered in many European countries and will help to reduce the risk of cervical cancer, but it will not abolish it and cervical screening will remain a critical public health intervention.

How is cervical cancer treated?

Abnormal cells can be removed before they become cancerous using surgery, freezing or a laser. Treatment of cancer may involve one of or a combination of:

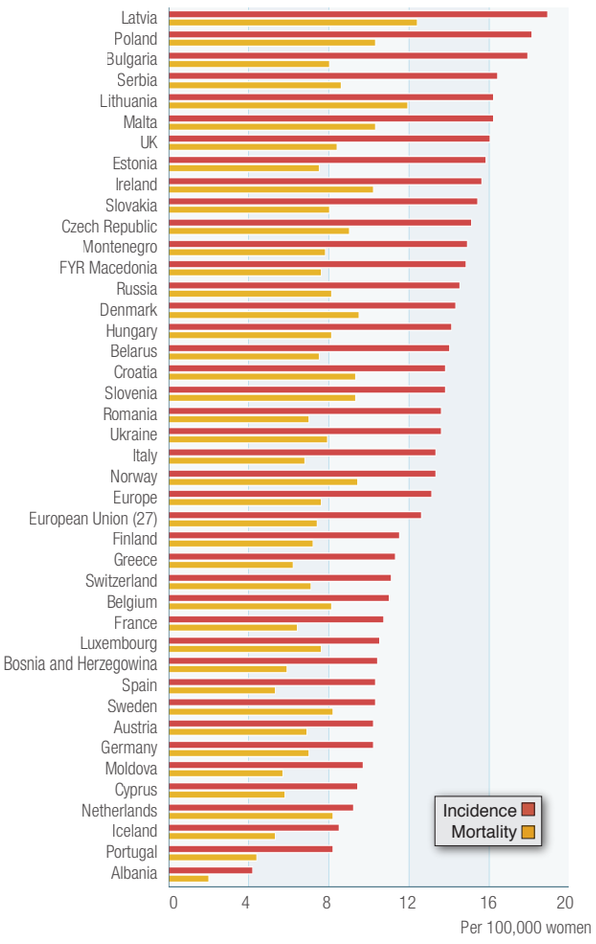
- **Surgery,** which can cure early cancers limited to the cervix and surrounding tissues. Some women with early cervical cancer may be offered a fertility-preserving radical trachelectomy or cone biopsy.
- **Radiotherapy** can cure early cancers, and it is also used to destroy any remaining cancer cells after surgery or to relieve symptoms. It is also highly effective against advanced cancers with or without chemotherapy.
- **Chemotherapy** is given to shrink advanced cancers and relieve symptoms. It is also sometimes used before surgery or radiotherapy.

Ovarian cancer

The ovaries are two oval glands that lie on either side of the womb and just below the opening to the fallopian tubes. In addition to producing eggs or 'ova', the ovaries release the female sex hormones oestrogen and progesterone.

Ovarian cancer is the sixth most common cancer among women in Europe, with over 65,000 cases in 2012.[3] Europe in general has one of the highest incidences of ovarian cancer in the world,[10] but rates are highest in Eastern and Northern Europe and lowest in Southern Europe.[2]

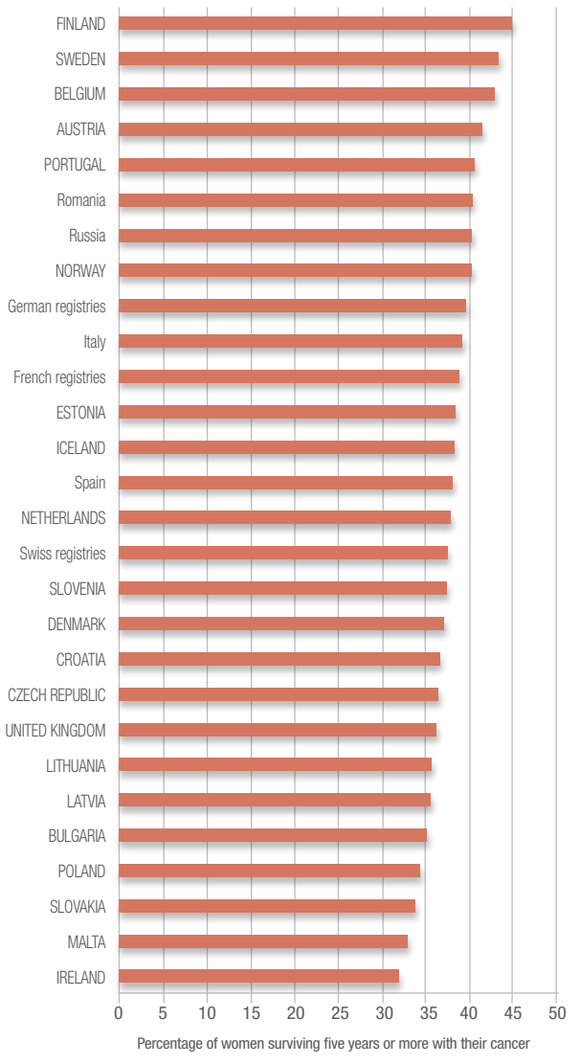
Ovarian cancer: estimated incidence and mortality 2012[2]



In Europe, about one third of women can expect to be alive five years after a diagnosis of ovarian cancer.[2] But five-year survival is strongly related to the stage at which the cancer is detected, and is poor in advanced disease. There is regional variation within Europe with survival low in many Eastern European Countries and the United Kingdom.[5]

As with most cancers, different subtypes are being recognised that have differing outcomes and respond differently to conventional and targeted therapies. High-grade serous cancer is the most common subtype, and also the most sensitive to chemotherapy.

Ovarian cancer: five-year net survival[5]



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What causes ovarian cancer?

Most ovarian cancers develop after the menopause. Apart from age, factors that may increase a woman's risk include:[7,11]

- Early onset of periods and late menopause
- Having no or few children
- Long-term use of hormone replacement therapy (though the oral contraceptive pill may reduce risk)
- Endometriosis is associated with a small increase in risk of ovarian cancer, as is a history of benign (non-malignant) ovarian tumours
- Obesity
- Height
- Diet high in saturated fat
- Smoking
- Previous breast cancer
- Mother or sister with ovarian cancer
- BRCA genes (see Inherited cancers, page 18).

How is ovarian cancer diagnosed?

The early symptoms of ovarian cancer are often vague. But a woman, especially if she is aged over 50, may have ovarian cancer if the following symptoms persist and occur frequently:

- Abdominal distension (swelling)
- Feeling full (bloating) in the abdomen and/or loss of appetite
- Pain in the lower abdomen or side.

Tests to confirm the diagnosis include:

- Internal examination and external examination of the abdomen
- Blood test to check levels of CA125 and other tumour markers
- Ultrasound and other scans such as computed tomography (CT) and magnetic resonance imaging (MRI) scans
- In some women with suspected cancer, laparoscopy may help in exploring the inside of the abdomen.

How is ovarian cancer treated?

- **Surgery** is recommended for most women with ovarian cancer. The operation typically involves a hysterectomy, salpingo-oophorectomy and omentectomy. This is a major operation, and should be undertaken only by highly specialised surgeons in expert centres. Other tissues in the abdomen and pelvis will be closely examined, including the bowel and lymph nodes, and may also be removed if the cancer has spread. In some cases of early ovarian cancer, fertility-sparing surgery may be possible.

- **Chemotherapy** is usually given after surgery to stop the cancer from recurring, but it is also given to shrink the cancer before surgery, especially in advanced cases. It is also used in recurrent disease. Most regimens are based on platinum agents, and an increasing range of targeted therapies is becoming available. Maintenance therapies with bevacizumab, an antibody that interferes with the blood supply to cancers, is becoming established in many countries after or alongside treatment with platinum-based chemotherapy. Chemotherapy may also be given directly into the abdomen (called intraperitoneal chemotherapy). Trials are also underway to assess the role of this type of treatment when used with heated chemotherapy (HIPEC).

- **Radiotherapy** is rarely used in ovarian cancer, but may be used in late-stage disease to relieve symptoms such as pain or bleeding.

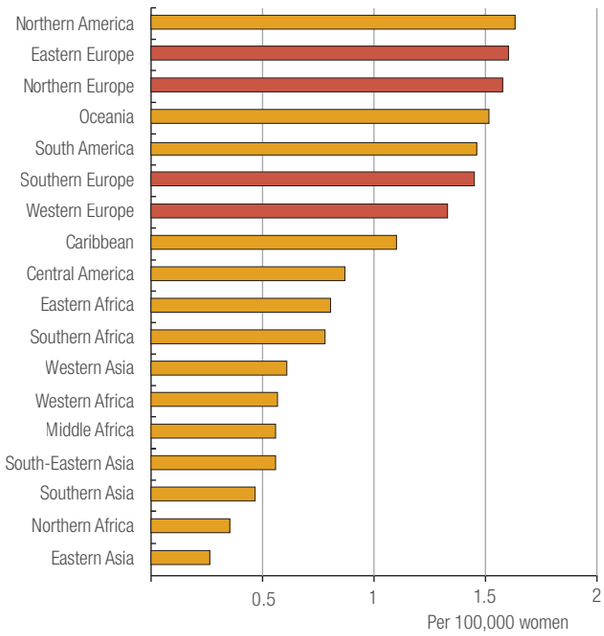
Can women protect themselves against ovarian cancer?

At present, there are no tests that can reliably identify women with early ovarian cancer. But greater awareness among women (and their family doctors) that abdominal bloating or distension is a common early symptom could mean that more women are diagnosed when their cancer can be cured. Women at high risk because of family history (see Inherited cancers, page 18) should also have regular gynaecological examinations. While the evidence of an association is not strong, it is advisable for all women to use the lowest dose of hormone replacement therapy for the shortest time to treat menopausal symptoms. There is currently no screening for ovarian cancer, but results of the United Kingdom Collaborative Trial of Ovarian Cancer Screening (UKCTOCS) should be available towards the end of 2015. As a substantial proportion of ovarian cancers arise from the fallopian tubes, their removal as a preventive measure at the time of hysterectomy for other reasons is also currently under evaluation.

Vulval cancer

The vulva is made up of several external organs, including the inner and outer lips (labia), the clitoris, and the openings of the vagina and urethra (the tube from the bladder). Vulval cancer is rare, accounting for 3% of cancers of the genitals in women.[7]

Vulval cancer: estimated global incidence, 2002[12]



Globally, about 27,000 women are diagnosed each year with vulval cancer.[12] Within Europe, women in eastern and northern countries are at highest risk, while risk is lowest in western and southern countries.

Over eight out of 10 women with early vulval cancer will be alive five years after their diagnosis, but five-year survival in advanced disease is low.[13] Women aged over 65 are at highest risk of developing vulval cancer, but rates are increasing in younger women, probably because of rising rates of HPV infection and cigarette smoking.[14]

What causes vulval cancer?

Most vulval cancers are preceded by abnormal changes to the skin cells of the vulva, called vulval intraepithelial neoplasia (VIN). VIN may be basiloid (warty) or undifferentiated, and the type usually depends on the woman's age:[15]

- Basiloid VIN is more common in younger, premenopausal women and is associated with cancer-causing HPV
- Undifferentiated VIN is more common in older, postmenopausal women and is often associated with lichen sclerosus, a common skin condition of the vulva that causes it to become red and sore.

Other factors that increase the risk include:[16]

- Previous cervical cancer or abnormal changes to the cells of the cervix
- HIV or immunosuppression
- Sexually transmitted infections
- Smoking.

How is vulval cancer diagnosed?

Symptoms of vulval cancer include:

- Long-lasting itching that does not respond to or returns after usual treatment
- Bleeding
- Pain or soreness
- Thickened red, white or dark patches on the vulva
- Vaginal discharge or bleeding
- Burning pain on passing urine
- A sore, growth or lump on the vulva
- A mole on the vulva that changes shape or colour.

Tests to confirm the diagnosis include:

- External examination of the vulva and internal (pelvic) examination
- Biopsy of a sample of vulval tissue
- Examination of the inside of the bladder and rectum to see if the cancer has spread from the vulva
- Scans to check the cancer has not spread to the rest of the body.

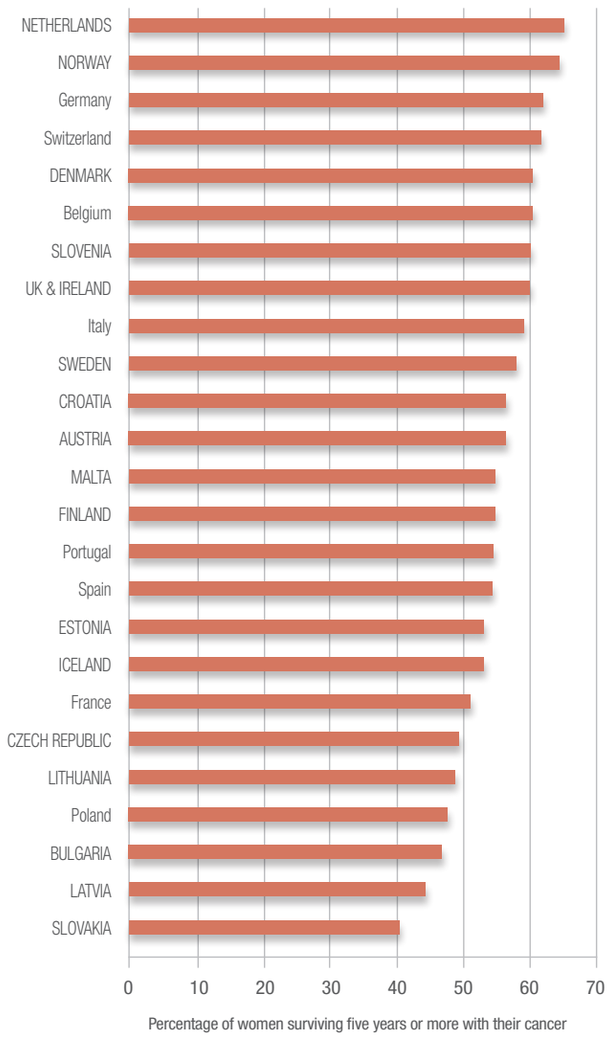
How is vulval cancer treated?

- **Surgery** is the most common treatment for VIN and vulval cancer. This involves either removal of the affected area, usually the groin lymph nodes, or in some cases complete removal of the vulva and any affected organs in the pelvis. Sometimes VIN can be treated with a laser rather than surgery.
- **Radiotherapy** is given before or after surgery. It may be the main treatment for women who are not fit enough for surgery and may be given with chemotherapy.
- **Chemotherapy** may be given with radiotherapy or if the cancer returns and further treatment is needed. VIN may sometimes be treated medically using imiquimod cream.[17]

Can women protect themselves against vulval cancer?

There are no specific screening programmes for vulval cancer, but VIN can be diagnosed during cervical screening. Women can also use a mirror to check the vulva regularly, so that they can report any abnormal changes to their doctor. It is also important to ask the doctor about symptoms of thrush (Candida) that do not clear up with usual treatment or recur frequently. This is because persistent itching, pain or soreness may rarely be signs of vulval cancer.

Vulval and vaginal cancers: five-year relative survival[18]



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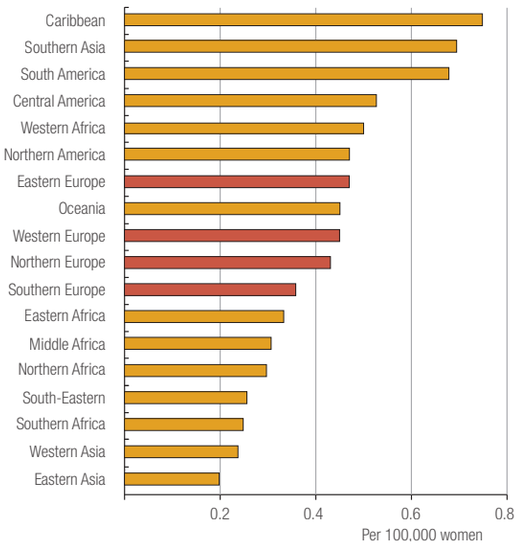
Vaginal cancer

The vagina is a muscular passage that connects the cervix (neck of the uterus) with the external genitals. Primary vaginal cancer - cancer that begins in the vagina - is rare, accounting for less than 2% of cancers of the genitals in women.[19]

Estimated global incidence of vaginal cancer, 2002[12]



Each year, about 13,200 women in the world are diagnosed with primary vaginal cancer.[12] Within Europe, the incidence is highest in Eastern Europe and lowest in Southern Europe. These differences are probably due to varying levels of long-lasting HPV infection as well as lack of cervical screening programmes, since these can identify early signs of vaginal cancer.

The outlook is good if vaginal cancer is diagnosed in its early stages, with 95% of women alive five years after their diagnosis. However, five-year survival is very poor for women with advanced disease.[20]

What causes vaginal cancer?

The risk of vaginal cancer rises with age, and most affected women are aged over 60. Apart from age, factors that increase the risk of primary vaginal cancer include:[21]

- Abnormal, precancerous changes to the vaginal epithelium called vaginal intraepithelial neoplasia (VAIN), caused by long-lasting infection with cancer-causing HPV
- Precancerous changes to the cervix or cervical cancer
- HIV or AIDS
- Treatment for uterine cancer, especially radiotherapy
- Smoking.

How is vaginal cancer diagnosed?

VAIN and early vaginal cancer may be identified during cervical screening. Otherwise, symptoms may only appear when the disease is advanced. The most common symptom is abnormal vaginal bleeding:

- Between periods and after sex before the menopause
- At any time in postmenopausal women.

Other possible symptoms include:

- Vaginal discharge that is blood stained or smells unpleasant
- Pain during sex
- A lump in the vagina
- An itch in the vagina that does not go away with usual treatment.

Tests to confirm the diagnosis include:

- Internal pelvic examination and Pap smear
- Colposcopy
- Biopsy of a sample of tissue from the vagina
- Examination of the inside of the bladder and rectum to see if the cancer has spread from the vagina
- Scans to see if the cancer has spread to the rest of the body.

How is vaginal cancer treated?

- **Surgery** can be used to remove cancers, whether they are limited to the vagina or have spread to surrounding organs. Plastic surgery is sometimes possible to rebuild the vagina.
- **Radiotherapy** is frequently used, either internally or externally. The aim is to cure the cancer and preserve the vagina and surrounding organs.
- **Chemotherapy** is usually used in combination with radiotherapy. It rarely used by itself except when the cancer is advanced or has returned after previous treatment.

Can women protect themselves against vaginal cancer?

There are no specific screening programmes for vaginal cancer. However, precancerous changes to the vagina can be identified during cervical screening so that women can be offered treatment. Women can also use a mirror to check the vaginal area regularly for any problems that might be early signs of cancer. By becoming more aware of the risks of cancer in this area, women can ensure that they see a doctor if there are any abnormal changes.

Uterine cancer

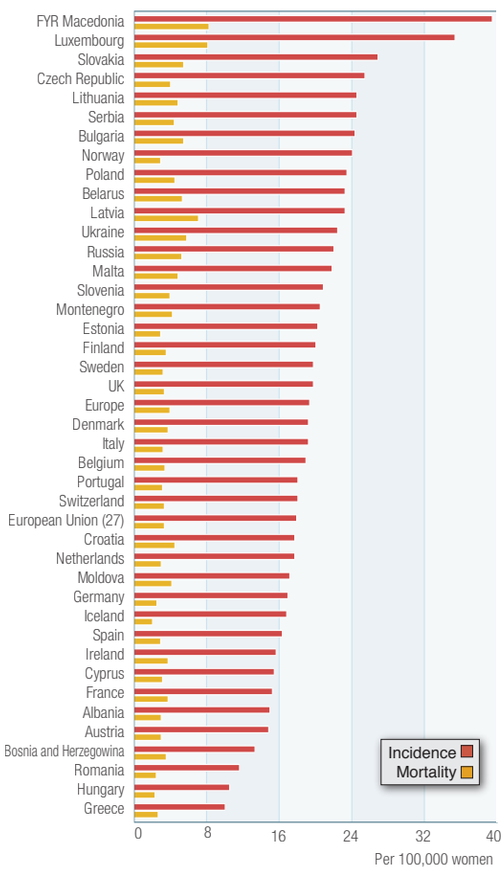
What is uterine cancer?

The uterus or womb is the hollow, muscular organ in which the baby develops during pregnancy. The most common type of uterine cancer is endometrial cancer, which develops from the lining of the womb (the endometrium). There are two types of endometrial cancer, which look different under the microscope and are likely to need different forms of treatment:[7]

- **Type 1** cancers amount for more than 80% of endometrial cancers. They are linked to excess oestrogen in the body, and are usually slow growing and less likely to spread beyond the womb.
- **Type 2** cancers are not related to oestrogen, grow more quickly and are more likely spread to other parts of the body.

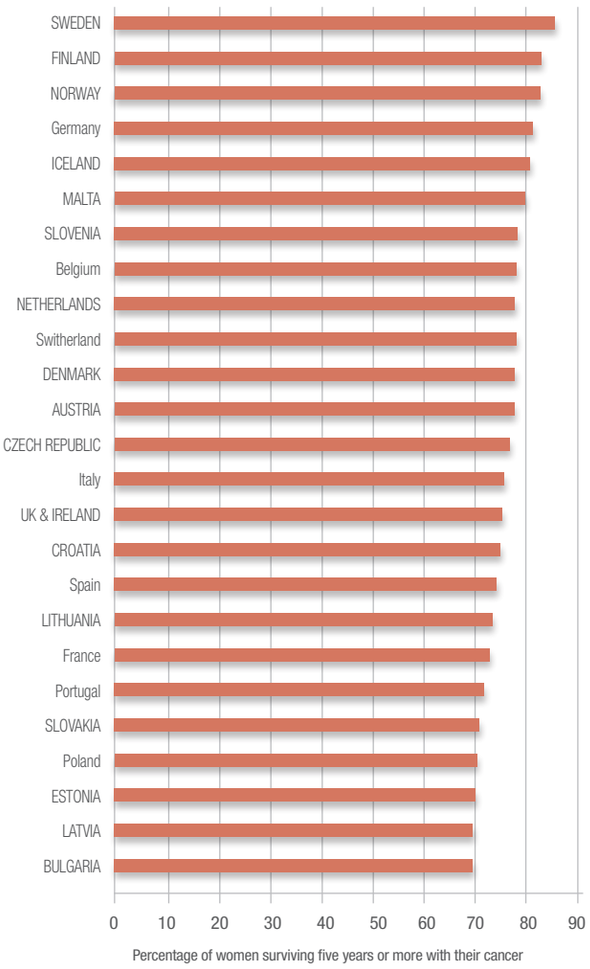
Europe has some of the highest rates of uterine cancer in the world; more than one in 20 female cancers affect the endometrium, and the number of cases is increasing.[22] This is partly because of the ageing of the European population, but rising rates of obesity are known to be an important contributory factor.[23]

Uterine cancer: estimated incidence and mortality, 2012[2]



The outlook is relatively good for women diagnosed with uterine cancer in Europe. On average, nearly 80% are alive five years after their diagnosis.[2]

Uterine cancer: five-year relative survival[18]



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What causes uterine cancer?

The causes of uterine cancer are unclear, but factors that increase a woman's risk include:[7,24]

- Advancing age: most cases are diagnosed after the menopause
- More exposure to the female hormone oestrogen, e.g. through early onset of periods or late menopause
- Obesity, probably because obesity raises oestrogen levels
- Diabetes and polycystic ovary syndrome, possibly because both conditions involve resistance to the effects of insulin, which can stimulate the growth of cancer cells
- Other previous cancers, such as breast, colon or rectum
- A mother or sister with endometrial cancer
- Hereditary non-polyposis colon cancer (HNPCC), also known as Lynch syndrome, an inherited condition that increases the risk of uterine cancer at a younger age (see page 18)
- Long-term treatment with tamoxifen, a drug given to prevent breast cancer recurrence
- Not bearing children.

How is uterine cancer diagnosed?

The first symptom of uterine cancer is usually abnormal vaginal bleeding:

- Before the menopause, bleeding between periods or after sex
- After the menopause, bleeding at any time.

Other symptoms include:

- Pain during or after sex
- Vaginal discharge
- Pain in the lower abdomen.

Tests to confirm the diagnosis include:

- Internal pelvic examination
- Swab to check if cancer is present in the cells of the cervix
- Biopsy of the endometrium
- Ultrasound scan via the vagina (transvaginal ultrasound)
- Hysteroscopy and curettage.

How is uterine cancer treated?

- **Surgery** is recommended for all women with uterine cancer who are fit enough for the operation. The type of surgery depends on the woman's cancer, but most women are recommended to have their womb, fallopian tubes and ovaries removed. Lymph glands are sometimes removed at the same time to check if further treatment is needed.
- **Radiotherapy** is given as the main treatment for less fit women, or when surgery cannot remove all the cancer. It is also given post-operatively to reduce the risk that the cancer will recur. Radiotherapy can be given in two ways: either externally to the whole pelvis or internally via a narrow central tube of tissue (brachytherapy). Since radiotherapy can cause long-term side effects, research is under way to investigate the best time to give this treatment and to identify women who are most likely to benefit.
- **Hormone therapy** with progesterone is used to shrink cancers that have spread to the rest of the body, or to prevent cancer from returning. This treatment may also be offered to some younger women with very early uterine cancer who want to preserve their fertility.
- **Chemotherapy** is increasingly used in women who present with advanced uterine cancer, and platinum- or doxorubicin-based combinations of drugs can produce dramatic improvements. However, the side effects of chemotherapy may mean that it is less suitable for women with other serious health problems, such as heart disease.

Can women protect themselves against uterine cancer?

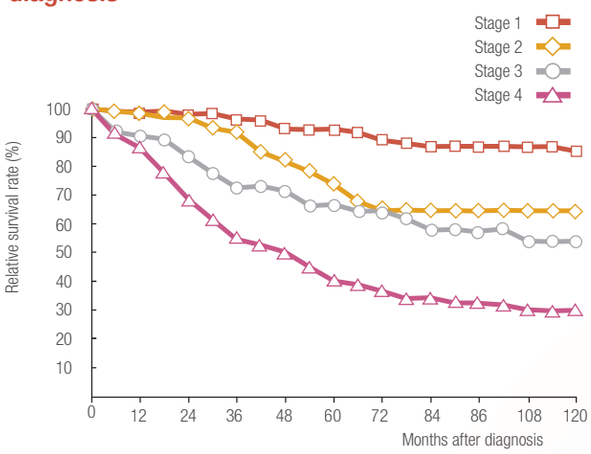
There are currently no screening tests, but uterine cancer can be treated successfully if it is diagnosed at an early stage. Although most women with abnormal vaginal bleeding do not have uterine cancer, it is vital for every woman to consult her doctor as soon as possible if she experiences this symptom, especially after the menopause. Women who are at high risk of uterine cancer because of their family history should have regular gynaecological examinations.

Several factors are thought to reduce a woman's risk of developing uterine cancer.[24-26] Lifestyle factors include maintaining a healthy weight to avoid obesity, being physically active, and coffee drinking (both caffeinated and decaffeinated). If taken long term, most modern birth control pills (combination pills containing oestrogen and progesterone or progesterone-only 'mini-pills') will reduce the risk. Continuous combined hormone replacement therapy (HRT), which combines daily oestrogen and progestogen, also reduces a woman's risk of uterine cancer, but at the same time increases her risk of developing breast cancer.

Fallopian tube cancer

The fallopian tubes are thin tubes that link the womb to the ovaries. Cancer beginning in the fallopian tubes - primary fallopian tube cancer - was thought to be very rare, accounting for around 1% of all female genital cancers. However, primary fallopian tube is likely to occur more frequently, since many ovarian cancers appear to originate in the fallopian tubes rather than in the ovaries.[27]

Fallopian tube cancer: survival rates by stage at diagnosis[28]



An estimated 5000 women in Europe are thought to have fallopian tube cancer.[29] Because the disease is so rare, it is unclear if women in particular regions of Europe are more likely to develop this type of cancer. However, the risk of fallopian tube cancer has generally risen since the 1950s, especially in women aged over 55 years.[30]

The likelihood of being alive five years after being diagnosed with fallopian tube cancer is about 65% or higher.[30] Studies in the USA suggest that survival is longer in younger women with fallopian tube cancer because they are generally diagnosed at an earlier stage of the disease when treatment is more likely to be successful.[28]

What causes fallopian tube cancer?

The risk of developing fallopian tube cancer is highest in women aged over 60 years. The risk also seems to be higher in women of higher social classes and education.[27] Other factors that might increase a woman's risk include:[30]

- Ovarian cancer in a close relative such as a mother, sister or daughter
- BRCA genes (see Inherited cancers, page 18)
- Previous cancer, especially breast
- Having no children.

How is fallopian tube cancer diagnosed?

Fallopian tube cancer may be found incidentally during surgery to remove the ovaries and fallopian tubes.[31] Otherwise, symptoms are similar to those experienced by women with ovarian cancer:

- Abnormal vaginal bleeding unrelated to periods in younger women, or at any time after the menopause
- Pain in the lower abdomen
- Vaginal discharge that may contain blood
- A swollen abdomen.

Tests to confirm the diagnosis include:

- Examination of the pelvis and abdomen
- Internal examination to check for any abnormalities
- CA125 blood test
- Scans to check the fallopian tubes, the abdomen and the rest of the body.

How is fallopian tube cancer treated?

- **Surgery** is the first option for most women. For early cancers, only the affected fallopian tube and ovary may need to be removed, together with the omentum. But in general women need hysterectomy.

- **Chemotherapy** is given after surgery if it was not possible to remove all the cancer, and to prevent the cancer from recurring. In general, women with fallopian tube cancer receive the same regimens used to treat ovarian cancer.

- **Radiotherapy** may be given occasionally to treat symptoms when the cancer has spread to the rest of the body

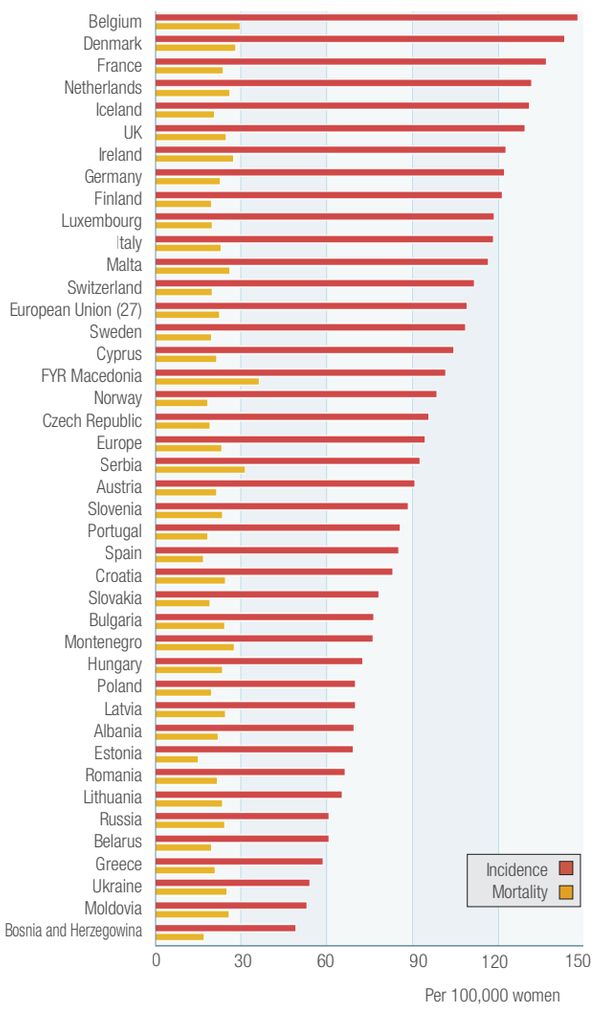
Can women protect themselves against fallopian tube cancer?

There is at present no reliable test that can identify women with fallopian tube cancer. Having children and using the oral contraceptive pill seem to reduce a woman's risk of fallopian tube cancer.[30] Otherwise, it is likely that a healthy lifestyle will help to reduce the risk of fallopian tube cancer along with other cancers.

Breast cancer

Breast cancer develops in the lining of the lobules, which make milk after childbirth, and in the ducts, the channels that take milk from the lobules to the nipples. The proportion of ductal tumours has recently increased, and over 80% of breast cancers now begin in the ducts.[1]

Breast cancer: estimated incidence and mortality, 2012[2]

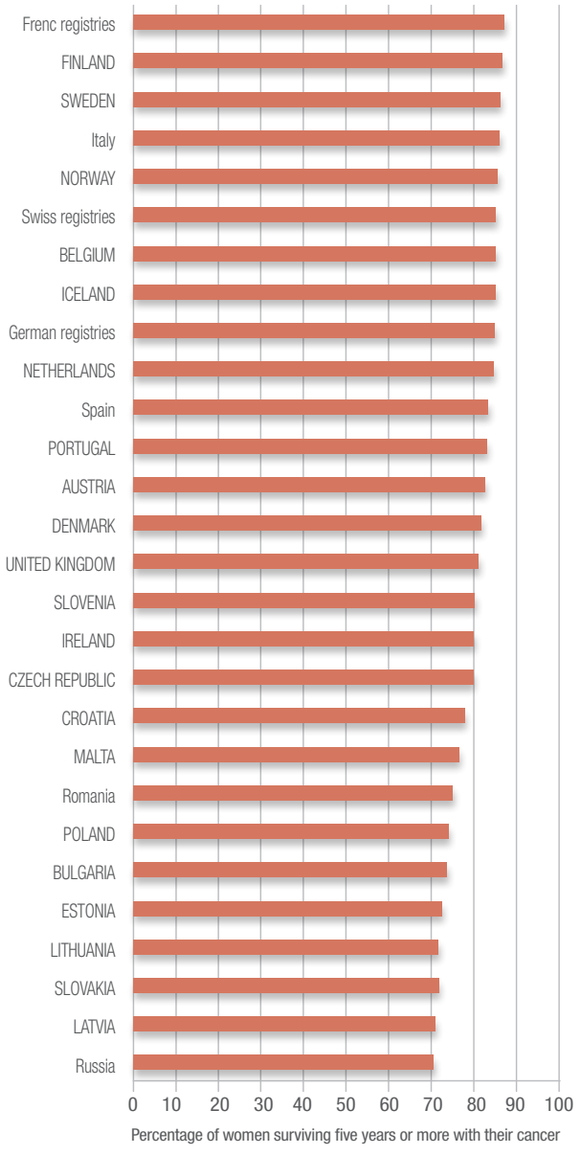


Breast cancer is the most common cancer in women in Europe, with over 463,000 cases in 2012.[2] The risk rises with age, with about two thirds of breast cancers occurring women over the age of 50 years.[32] Unlike many gynaecological cancers, breast cancer is most common in Northern and Western Europe.[2]

Breast cancer is responsible for more deaths among European women than any other cancer, but survival has improved thanks to screening and better treatments.[2]

Taking Europe as a whole, over 80% of women can expect to be alive five years after their breast cancer diagnosis.[5] Survival is higher in Western than in Eastern Europe, and there are differences within Western Europe: survival is lower in the United Kingdom and Denmark than in Finland, Sweden, Spain, Italy and the Norway.[5]

Cervical cancer: five-year net survival[5]



Note: ALL CAPITALS indicate that the statistics are for the country's total population; in other countries shown only part of the population is covered by cancer registration

What causes breast cancer?

Most cases of breast cancer occur in women aged over 50, and it is one of the few cancers where the risk is higher for more affluent women. Other factors increasing the risk include:[7]

- Late puberty and early menopause
- Having no children, or first child after the age of 30
- Current or recent use of oral contraceptives
- Current or recent use of combined hormone replacement therapy
- Excess body weight and physical inactivity
- Three or more alcoholic drinks a day
- Family history of breast cancer
- Previous radiotherapy
- BRCA genes (see Inherited cancers, page 18).

How is breast cancer diagnosed?

Very early breast cancer may have no symptoms and can only be detected on mammography screening. When symptoms occur, they may include:

- A painless lump that can be felt in the breast
- Change in the size or shape of the breast
- Altered skin texture, such as dimpling or thickening
- Inversion of the nipple
- Rarely, a discharge from a nipple or breast pain.

Tests to confirm the diagnosis include:

- Examination of the breasts and armpits
- Mammogram
- Ultrasound scan and other scans
- Biopsy of the lump.

How is breast cancer treated?

- **Surgery** is the first treatment for most women. When cancer is confined to the lobes or ducts, women may be offered lumpectomy, but other women will need mastectomy. Breast reconstruction may be possible.

- **Radiotherapy** is given after surgery to destroy any remaining cancer cells, and if necessary to treat cancer that has spread to the rest of the body.

- **Chemotherapy** and hormone therapy are given before surgery if the cancer has spread to tissues near the breast, and to women whose cancer has spread to the rest of the body. Postmenopausal women with early oestrogen receptor-positive breast cancer are offered hormone therapy to reduce the risk that the cancer will recur. Chemotherapy is recommended for other women.

Can women protect themselves against breast cancer?

A healthy lifestyle will help to reduce the risk of breast cancer and other serious diseases. Drugs such as tamoxifen can be used to prevent breast cancer in women who are at high risk of inherited breast cancer.[33]

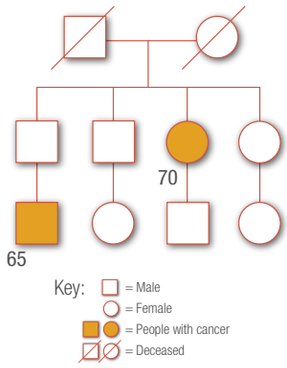
Most European countries have established or are introducing some form of breast cancer screening with mammography, though the ages and intervals for screening vary. There is little evidence that regular self-examination reduces the risk of death from breast cancer, but women should be 'breast aware' and see their doctor if they see any unusual changes in their breasts.

Family risk

Most gynaecological and other cancers sporadic; that is, the cancer occurs by chance, due to the effects on the body of a person's lifestyle and surroundings. However, a minority of women are more likely to develop cancer, including gynaecological cancers, because they have a familial or inherited risk.

Familial cancers

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

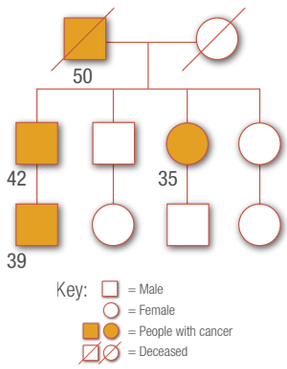


Numbers are ages at onset of cancer

Women in affected families are more likely to develop breast cancer if they have a mother, sister or daughter with the disease, the risk increasing with the number of affected relatives. However, even when several relatives are affected, most women will not develop familial breast cancer.[34]

Inherited cancer

In contrast, when a parent has a predisposition to cancer because of an inherited mutation or change in a single gene, each female child has a one in two chance of developing certain gynaecological and other cancers. Factors suggesting that a woman may be at risk of inherited cancer include:



Numbers are ages at onset of cancer

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

About 4% of all cancers are inherited.[35] Two types of genetic mutation are known to increase the risk of inherited gynaecological cancers:

- Hereditary breast-ovarian cancer syndrome (HBOC) is the result of mutations in either the BRCA1 or BRCA2 genes. It is thought that 13-18% of breast cancers can be traced to BRCA mutations, and they also contribute to the development of ovarian and fallopian tube cancers.[35]
- Hereditary non-polyposis colorectal cancer (HNPCC; also known as Lynch syndrome) is caused by a mutation in at least one of five genes: hMSH2, hMLH1, hMSH6, PMS1 and PMS2. By the age of 70 years, women with HNPCC have a 30-40% lifetime risk of uterine cancer and a 9-12% lifetime risk of ovarian cancer, as well an increased risk of developing bowel and stomach cancer.[36]

Genetic testing can identify the risk for each woman in affected families, but the decision to undergo testing is never straightforward. While unaffected women may be reassured, a positive test can result in anxiety for the future and concern about possible risks to children. In the near future, BRCA carriers may be treated with new drugs that seem to have an enhanced effect in BRCA-deficient tumours.

Counselling is essential so that women understand the possible benefits and disadvantages of genetic testing. Equally, women must be counselled about test results, so that they can make informed decisions about how to reduce their risk of inherited cancer.

Can women reduce their risk of inherited cancer?

Early diagnosis of inherited cancer is possible through regular monitoring, for example by mammography or other scans. Women can also reduce their risk by maintaining a healthy lifestyle, and by taking medication. Tamoxifen reduces the risk of developing breast cancer,[33] while combined oral contraceptives reduce the risk of ovarian cancer.[37]

However, because their risk of inherited gynaecological cancers can be so high, women may prefer to opt for preventive surgery. Removal of the fallopian tubes and ovaries prevents ovarian cancer and halves the risk of breast cancer. Similarly, mastectomy will virtually abolish the risk of breast cancer in women with BRCA1 or BRCA2 mutations, especially if their ovaries are also removed.[7]

PATIENT ADVOCACY: UNDERSTANDING THE ISSUES

Patient organisations face many challenges when they seek to raise awareness and improve the care of gynaecological cancers. Many of these issues cross national boundaries, and through joint advocacy patient organisations can raise standards of cancer care and address inequalities throughout Europe.

Preventing women's cancers

Public education

Prevention of gynaecological and other cancers must begin with public education that a healthier lifestyle can reduce the risk of many cancers and at the same time improve general health. Since the European Code Against Cancer was first issued in 1987,[38] there has been some progress in promoting healthier lifestyles - for example, in national legislation against tobacco smoking. But rising rates of obesity and concern about alcohol intake underline the continuing importance of public awareness initiatives that draw lessons from successful campaigns about the dangers of tobacco use.

Screening

In general, it is not possible at present to screen effectively for most cancers, including all rare cancers, so screening is generally relevant only to the most common cancer types with effective screening tests, such as breast, cervical and bowel cancer. Since 2003, European countries have been encouraged to implement nationwide, population-based screening programmes for breast and cervical cancer. Although programmes have been introduced in many countries, they do not always follow best-practice recommendations designed to ensure that all at-risk women are screened. Furthermore, genetic testing is not yet available throughout Europe to identify women at high risk of inherited ovarian, uterine or breast cancer.

Vaccination

While screening must remain the priority as a public health issue, many cases of cervical cancer could ultimately be prevented by vaccination against HPV. Many Western European countries have made HPV vaccination available, but few have introduced programmes that ensure optimum coverage. Indeed, HPV vaccination is generally offered in Western European countries with lower rates of cervical cancer, while some Eastern Europe countries with the highest rates are yet to implement any form of programme.[39] These wide variations must be urgently addressed to avoid perpetuating current inequalities in cervical cancer risk.

Promoting good practice in cancer care

Organisation of cancer care

Any woman with a gynaecological cancer should receive care from doctors who have undergone specialist training according to guidelines from ESGO. But women in Europe may still be cared for general physicians, surgeons or radiologists. Cancer outcomes are generally better when women receive care from specialists, but this is likely to be especially important for women with rare cancers. Specialists are more experienced in diagnosing and staging disease, and in using the range of available treatments for each gynaecological cancer. Specialists also find it easier to keep up to date with new developments, and can participate more readily in multidisciplinary teams.

Multidisciplinary cancer care

Multidisciplinary gynaecological cancer teams, which include doctors, specialist nurses, pharmacists, physiotherapists, psychologists and members of other disciplines, ensure that the best decisions can be made for each woman with gynaecological cancer. Although these gynaecological cancer teams are based in cancer centres in some countries, each country must adapt the multidisciplinary model according to the needs of its population.

But, however it is organised, to be successful,multidisciplinary cancer care must be co-ordinated to ensure seamless diagnosis and treatment. Each patient's case should also be routinely discussed at Tumour Boards (also known as Multidisciplinary Team or MDT meetings). Regularly updated guidelines are also an integral part of care, and ESGO plays a major part in maintaining these in collaboration with sister organisations.

Individualised treatment

There is increasing evidence that health professionals' adherence to clinical guidelines is critical to improving the care of gynaecological cancers, and ESGO has played a leading role in standardising and regularly updating these

guidelines. At the same time, the individual patient must always be the focus of the multidisciplinary cancer team. Treatment decisions will be influenced by a woman's age and the stage, grade and increasingly the genetics of her cancer. But professionals must also take into account each woman's personal needs and preferences. As more women survive gynaecological cancer, these considerations must include special issues such as the preservation of fertility, a woman's sexual feelings, and continuing psychosocial support to help women to live well with their cancer.

Fertility preservation

Preservation of fertility is an increasingly important issue in the care of survivors of gynaecological cancer. This is due both to rising rates of gynaecological cancer in young women and the general trend to older age at first pregnancy. Today, depending primarily on the extent and type of cancer, fertility preservation is possible in a young patient with gynaecological cancer. But a survey by the ESGO Task Force for Fertility Preservation raised important questions about the quality of care in Europe in terms of use of fertility-sparing treatment.[40] Since carrying out the survey, the Task Force has developed a protocol for referrals to centralised units with specific expertise in fertility preservation. Optimal management for young patients with gynaecological cancer should include a clear decision-making process, adequate counselling about future oncological and obstetric risks, appropriate management and careful follow-up within a multidisciplinary setting.

Cancer plans

Healthcare systems and national resources vary greatly within Europe. But it is possible for all countries to offer all women co-ordinated, multidisciplinary care for gynaecological cancers based on a national cancer plan (NCP). Regardless of national wealth, a well-conceived, well-managed NCP can improve the lives of patients by setting priorities and effectively allocating resources both nationally and across Europe. Some EU Member States have initiated cancer plans, or are in the process of establishing them, but the breadth and depth of these plans vary greatly. Pan-EU initiatives like the European Partnership for Action Against Cancer (EPAAC) aim to investigate the state of play in the development of NCPs in terms of content and effectiveness, and facilitate the transfer of knowledge and expertise. It is also critically important for national patient advocacy groups to track progress on NCPs in their respective countries.

Research is a priority

Information

Research is a priority to improve the prevention, early detection, treatment and outcomes of gynaecological cancers. However, to translate research findings into strategies that will ultimately benefit patients, the general public and patient organisations, as well as scientists, must be informed about the conduct and results of research. While important steps have been taken to inform patients and physicians about clinical trials that test a new treatment against the current standard of care, information is too often fragmented across numerous databases and restricted to trial sponsors, regulatory authorities and English-language scientific publications. In addition, results of clinical trials are not widely known to both patients and treating doctors. All stakeholders must act jointly to improve the translation of the latest scientific knowledge into medical practice.

The patient contribution

Traditionally, health professionals, industry and politicians have determined priorities for cancer research, with little direct contribution from patients and the general public. There has been some progress in taking patients' views into account - for example, patient quality of life measures are now included in clinical trials. But action must be taken in all European countries to ensure that women with gynaecological cancer play an active role in formulating research programmes and monitoring their results.

Knowledge is power

Patient education

Successful breast cancer campaigns demonstrate that it is possible to raise awareness of gynaecological cancers and how to ensure optimal treatment and care. The early symptoms of some gynaecological cancers are difficult to recognise because they often vague or could be caused by other conditions. It is, however, possible to provide simple information designed to prompt women to consult a doctor. There are challenges, as some women may be too embarrassed or afraid to seek medical help. But campaigns to raise awareness of other sensitive issues, such as HIV/AIDS, demonstrate that open discussion can help to encourage affected patients to consult a doctor when there is the best chance of successful treatment. When women do seek medical health, they also need timely, high quality and up to date information on the diagnosis, treatment and care of their cancer.

Inequalities

When the first results of the EUROCARE study were published in 1995,[41] they provided the first credible information on cancer inequalities in Europe. Some countries had particular cause for concern: survival rates for cancer patients in Denmark and the United Kingdom were lower than for similar Western European countries. Public concern and campaigns by patient organisations have led these countries to take action to improve cancer services. However, recent studies confirm that survival disparities still exist in Europe despite national cancer plans.[4,5]

Cancer registries

EUROCARE and other studies continue to highlight the importance of information that compares cancer incidence, prevalence and survival in European countries. But accurate information on the performance of national care systems is only possible if countries introduce and maintain cancer registries that include complete and accurate information on all cancer patients.

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Glossary

AIDS
Acquired immunodeficiency syndrome.

Biological therapy
A drug that uses substances made from living organisms to treat disease. Some biological therapies stimulate or suppress the immune system to help the body fight cancer, while others attack specific cancer cells.

Biomarker
Chemicals and proteins in the blood that indicate that a cancer may be present, or that a cancer may respond to a particular drug.

Biopsy
Removal of a small sample of tissue so that it can be examined under a microscope to see if cancer cells are present.

Brachytherapy
Radiation treatment given by placing radioactive material in or near the tumour.

Breast reconstruction
Surgery following mastectomy or lumpectomy, designed to create a new breast shape or fill the area where tissue was removed. This may involve implants or natural tissues and may occur at the same time or after a breast cancer operation.

CA125
A protein produced by some gynaecological cancers. Levels may be normal in early disease, and a raised level may be due to cancer or other conditions such as fibroids, endometriosis or pregnancy.

CIN
Cervical intraepithelial neoplasia—changes in the cells of the cervix that may indicate the possibility of cancer.

Chemotherapy
Treatment that uses drugs to kill cancer cells.

Clinical trial
A research study, in which people volunteer to help doctors find ways to improve health and care. Each study tries to answer scientific questions and to find better ways to prevent, diagnose or treat cancer or other diseases.

Colposcopy
Detailed examination of the cervix using a magnifying instrument called a colposcope.

Cone biopsy
Remove of a cone-shaped wedge of abnormal tissue from the cervix for examination under a microscope.

Curettage
Removal of tissue by scraping, especially from the lining of the womb.

Grade
How far cancer cells resemble normal cells of the same type when examined under a microscope. Low-grade cancer cells are similar to normal cells, while high-grade cells look very different. The grade indicates how the cancer is likely to behave: a high-grade cancer may grow faster or be more likely to spread than a low-grade cancer.

HIPEC
Hyperthermic intraperitoneal chemotherapy - heated chemotherapy given into the abdomen by the surgeon at the end of an operation to remove intra-abdominal and pelvic cancers.

HIV
Human immunodeficiency virus.

HPV
Human papilloma virus.

Hysterectomy
Surgery to remove the womb and other tissues: a total hysterectomy involves removal of the womb and cervix; a subtotal hysterectomy leaves the cervix in place; total hysterectomy with bilateral salpingo-oophorectomy removes the womb, cervix, fallopian tubes and ovaries; radical hysterectomy involves removal of womb, fallopian tubes, ovaries, part of the vagina, lymph glands and fatty tissue.

Hysteroscopy
Examination of the inside of the womb using a hysteroscope, a narrow tube with a telescope at the end.

Incidence
The number of deaths or new cases of a disease that occur during a specific period of time, such as one year.

Internal examination
Examination of the womb and other pelvic organs via the vagina. The doctor will examine external tissues, and feel internal organs such as the cervix and ovaries.

Laparoscopy
Examination of the inside of the abdomen using a laparoscope, a narrow tube with a telescope at the end.

Lifetime risk
The chance that a person will develop a disease or die of that disease during her lifetime. This is often expressed as a percentage, or odds: for example, a 5% or 1 in 20 lifetime risk.

Lumpectomy
In breast cancer, removal of the cancer and a small area of surrounding healthy tissue, designed to conserve the breast.

Lymph glands
Small bean-shaped glands or 'nodes' that contain white blood cells. They are an important part of the immune system and are found throughout the body.

Mammogram
An X-ray of the breast, used in breast cancer screening programmes and to confirm a diagnosis of breast cancer.

Mastectomy
Removal of the entire breast. Lymph nodes may also be removed from under the arm if the cancer has spread.

Oestrogen
A female sex hormone released by the ovaries.

Oestrogen receptor
The growth of normal breast cells and some breast cancers is stimulated by oestrogen. Oestrogen receptors are molecules that catch the oestrogen circulating in the blood. The presence of the oestrogen receptor means that the cancer is likely to respond to hormone therapy.

Omentum
A large sheet of fatty tissue that covers the abdominal organs.

Omentectomy
Surgical removal of the omentum.

Precancerous
Changes in cells that may, but do not always, become cancer.

Prevalence
The proportion of people in the population who have a particular disease at a given time, usually expressed as a percentage.

Primary cancer
Cancer is usually named after the organ in which it begins, so cancer that starts in the ovary is primary ovarian cancer.

Primary prevention
Reducing the risk of a disease before it develops by, for example, weight loss or smoking cessation.

Progesterone
A female sex hormone released by the ovaries.

Radical trachelectomy
Removal of the cervix.

Salpingo-oopherectomy
Removal of an ovary (oophorectomy) and its fallopian tube (salpingectomy). In a bilateral salpingo-oopherectomy both sets of ovaries and fallopian tubes are removed.

Secondary cancer
A cancer that has grown as the result of spread from the organ in which it began.

Secondary prevention
Identification and treatment of the early signs of a disease before it causes serious problems.

Stage
The size of the cancer and how far it has grown. Early-stage cancer is limited to a single organ, while late-stage or advanced cancer has spread to the rest of the body. The earlier the stage, the more likely it is that the cancer can be cured.

Survival rate
The percentage of people still alive within a given period of time after their diagnosis or treatment. Five-year survival is the percentage of people expected to survive five years or longer.

Tumour markers
Proteins in the blood that may be raised in some gynaecological and other cancers if the cancer has spread (e.g. AFP, beta HCG, CEA, CA199, HE4 inhibin). Levels may also be increased in non-cancer-related conditions such as liver disease and inflammatory bowel disease.

Resources

European advocacy organisations (all cancers)

European Cancer Patient Coalition: www.ecpc.org
ECPC is the umbrella group of European cancer patients, established to represent their views in the European healthcare debate and provide a forum for patients to exchange ideas and share best practice experiences.

European Partnership for Action Against Cancer: www.epaac.eu
EPAAC is a multi-stakeholder 'joint action' initiative from the European Commission that brings together ministries of health, patient organisations, health professionals, scientists, industry and civil society to tackle cancer more equally and effectively across Europe.

European Patients' Forum: www.eu-patient.eu
The umbrella organisation of pan-European patient organisations active in public health and health advocacy, and the collective voice for patients across diseases at EU level. It currently represents over 60 patient organisations including chronic-disease-specific pan-European patient organisations and national coalitions of patient organisations.

EURORDIS: www.eurordis.org
A non-governmental, pan-European, patient-driven alliance representing more than 550 rare disease patient organisations in over 50 countries.

International Alliance of Patients' Organizations: http://iapo.org.uk
A unique global alliance, representing patients of all nationalities across all disease areas, that aims to promote patient-centred healthcare around the world. Its members are patient organisations working at international, regional, national and local levels to represent and support patients, their families and carers.

Rare Cancers Europe: www.rarecancerseurope.org
Rare Cancers Europe is a partnership of patient organisations, medical societies and industry, which aims to place rare cancers on the European policy agenda, identify and promote appropriate solutions, and share best practice.

Cancer information

CancerWorld: www.cancerworld.org
Cancer World is a journal that explores the complexity of cancer care, and offers readers insight into the decisions that shape professional practice. Cancer World is published six times a year by the European School of Oncology and is available free of charge. All articles are also published online.

EUROCARE: www.eurocare.it
A collaborative research project designed to analyse and compare the survival of cancer patients in the different countries of Europe. Information from the EUROCARE3, EUROCARE4 and EUROCARE5 databases is freely available online.

European Cancer Observatory: http://eu-cancer.iarc.fr
Comprehensive and authorative factsheets on the burden of cancer and deaths in individual countries and Europe as a whole.

European Code Against Cancer: www.cancercode.org
Information on the burden of cancer in Europe, and the European Code Against Cancer, designed to reduce this burden.

International Cancer Benchmarking Partnership:
www.cancerresearchuk.org/cancer-info/spotcancerearly/ICBP/
A global partnership of clinicians, academics and policymakers seeking to understand how and why cancer survival varies between countries/jurisdictions.

RARECARENet - Information Network on Rare Cancers:
www.rarecarenet.eu/rarecarenet
An EU-funded project that aims to build an information network to provide comprehensive information on rare cancers to doctors, researchers, health authorities, patients and their families.

World Cancer Research Fund International: www.wcrf.org
The world's leading authority on cancer prevention research related to diet, weight, physical activity.

World Health Organization Cancer Control: Knowledge into Action:
www.who.int/cancer/modules/en/
A WHO guide in six modules on effective programmes in cancer control, including prevention, early detection, diagnosis and treatment, palliative care, and policy and advocacy. The modules can be downloaded free of charge.

Union for International Cancer Control: www.uicc.org
UICC is the leading non-governmental, non-profit, non-political and non-sectarian cancer organisation. Its mission is to eliminate cancer as a life-threatening disease for future generations. UICC is committed to delivering the targets of the World Cancer Declaration (www.uicc.org/world-cancer-declaration) through strategic partnerships.

Patient advocacy resources

PatientPartner Project: www.patientpartner-europe.eu
PatientPartner was funded by the EU's 7th Framework Programme in the area of health and ran during 2008-2011. The aim of this project was to identify patients' needs for partnership in clinical trials and the resulting resources are available on the PatientPartner website. They include: guides for patient groups, sponsors and researchers on effective partnerships in clinical trials and clinical research; policy recommendations on patient Involvement in clinical research; and ethical principles of patient involvement.

Working with Partners and Stakeholders (IAPO Toolkit):
https://iapo.org.uk/working-partners-and-stakeholders-toolkit
Provides guidance on how patients' organisations, both large and small, can develop effective, long-term partnerships with a range of stakeholders.

ABOUT ESGO AND ENGAGE:
THE EUROPEAN VOICE OF GYNAECOLOGICAL ONCOLOGY!

The European Society of Gynaecological Oncology (ESGO) is the principal European society of gynaecological oncology contributing to the study, prevention and treatment of gynaecological cancer. Today, ESGO has members in over 40 countries in Europe.

ESGO's mission:

ESGO strives to improve the health and well-being of European women with gynaecological (genital and breast) cancer through prevention, excellence in care, high quality research and education.

What is ENGAGe?

Established in 2012, the European Network of Gynaecological Cancer Advocacy Groups is a network of European patient advocacy groups established by ESGO and representing all gynaecological cancers particularly (ovary, endometrial, cervix, vulva and rare cancers).

Why is ENGAGe needed?

- There are wide variations in patient care across Europe.
- Patients are not adequately informed about gynaecological cancers and their management.
- Survivorship issues are not adequately addressed and psychosocial support in general is poor.

The ENGAGe objectives are to:

- Facilitate the development of national gynaecological cancer patient groups in Europe and to facilitate networking and collaboration between them.
- Disseminate information and share best practices to empower patient groups and improve the quality of care across Europe.
- Increase patient representation in ESGO activities by education on current research and health policy.
- Advocate patient care policies, practices and access to appropriate care at both national and European levels.
- Educate patient groups, health professionals, the public and health decision makers.

ENGAGe
ESGO | European Network of Gynaecological Cancer Advocacy Groups

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The European Voice of Gynaecological Oncology