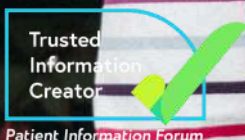


ovacome..
ovarian cancer

Is there screening for ovarian cancer?



Patient Information Forum

Ovacome is the UK's ovarian cancer support charity.

We provide support and information to anyone affected by ovarian cancer. This includes people who have either been diagnosed with the disease or think that they might be at risk, as well as their friends and family, and healthcare professionals.

Our free support services include:

- Telephone, email, text and instant chat support
- A 24-hour online forum
- Regional support and information events
- Online talks, workshops and support groups
- Expert information resources on ovarian cancer, to support with diagnosis, treatment and beyond

We also raise awareness of the signs and symptoms of ovarian cancer, and work alongside clinicians and researchers to ensure that patient voices are heard in the development of new policy and research on ovarian cancer. **For more information, please visit www.ovacome.org.uk**

This booklet is part of a series giving clinical information about ovarian cancer. It is for those who want to know what screening is available, how effective it is and what research is being carried out.

Our booklets can be downloaded or you can order printed copies by calling our support line on 0800 008 7054 Monday - Friday 10am-5pm.



Is there screening for ovarian cancer?

What is screening?

Screening is used to try to detect disease before it produces symptoms.

In the UK there are currently screening programmes for breast, cervical and bowel cancer. Before a screening test is made available on the NHS, it must be proved to be accurate, reliable, and safe.

There is currently no screening test for ovarian cancer but there are ongoing studies to find a suitable screening method.

Why is it important to have screening for ovarian cancer?

The early stages of ovarian cancer (stage 1 cancer in one or both ovaries) can usually be successfully treated. Unfortunately, most ovarian cancers are not found at this early stage for several reasons.

- Ovarian cancer appears more commonly after the menopause (when your periods have stopped). The ovaries are no longer active so if they behave abnormally, you may not notice.
- The ovaries are deep in the pelvis and are difficult to examine.
- Even when you have symptoms, they can be vague and not specific and could be due to other causes.

For these reasons, by the time ovarian cancer causes symptoms and is detected it has spread outside the ovaries to the pelvis (stage 2), abdomen (stage 3) or beyond the abdomen (stage 4). This makes it more difficult to treat.

This information suggests that an effective method of screening to find ovarian cancer at an early stage may save the lives of many of those who develop the cancer.

What investigations are available for ovarian cancer?

There are three tests for suspected ovarian cancer.

1. Physical examinations: An examination can be performed by a doctor to detect enlarged ovaries. It can detect large ovarian tumours, but even experienced doctors are not able to reliably detect ovarian cancer at an early stage. This means that it is not an effective method for detecting early ovarian cancer.

2. The CA125 blood test: A high level of CA125 is 35 or more for all people but this might be lower depending on how old you are. A high level of CA125 might mean you have ovarian cancer. The CA125 blood test is often used to check for ovarian cancer in those who have symptoms. It is also used to monitor patients during and after treatment for ovarian cancer to help detect potential recurrent disease.

However, CA125 is only raised in around 50 per cent (50 in 100) of early-stage ovarian cancers. A high level of CA125 can also be due other reasons, such as pregnancy, having a period, fibroids, and endometriosis. It is not specific to ovarian cancer.

3. Ultrasound: Ultrasound scans can be used to look at the size and texture of the ovaries. With ovarian cancer, the ovaries may be enlarged, and the texture may be abnormal. Some of these abnormal features are also found in non-cancerous ovarian tumours and other conditions in the pelvis. So, ultrasound results can be abnormal even when there is no cancer.

Ultrasound scans can be performed either by placing a probe on your abdomen or by putting a probe into your vagina (transvaginal scan). Trans-vaginal scans usually give a clearer picture of the ovaries.

Can these tests be used for screening?

Several large studies have looked at using CA125 or ultrasound to screen for ovarian cancer. They have shown that both tests can detect ovarian cancer before it causes symptoms. However, it is not clear if this screening saves lives from ovarian cancer.

Screening will only be worthwhile if it detects ovarian cancer early enough to make treatment more effective.

Large screening studies are in progress, and until they have reported their final findings, it is unclear whether screening can save lives or not.

What are the problems with screening for ovarian cancer?

The main problem is that the CA125 test and ultrasound scans can be abnormal in people who do not have ovarian cancer. These results, called false positives, often cause a great deal of anxiety.

Those with positive results might need an operation to rule out the possibility of ovarian cancer. Operations can have serious complications, and if no cancer is found, then the operation would be unnecessary.

As ovarian cancer is relatively uncommon, it means that more abnormal screening results are due to false positive findings rather than cancer. Most people find a negative screening result reassuring. However, the CA125 test or ultrasound scan will not pick up every ovarian cancer. These sorts of results, called false negatives, do happen. This means a small number of those screened will be wrongly told that they do not have cancer.

What have clinical trials shown?

UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS)

This very large randomised, controlled study of ovarian cancer screening was set up in the UK involving 200,000 women aged 50 to 74 years. The women were screened every year with CA125 testing or ultrasound.

The CA125 tests were looked at to see how they had changed over time. There was also a control group who are followed up without any screening.

The study reported its earliest results in 2016. These showed that this form of CA125 testing can detect ovarian cancer at a very early stage and it might save the lives of some of those participants who developed ovarian cancer during the time when they were being screened.

However, it did not provide enough evidence to prove this screening method would overall save women's lives from ovarian cancer.

The UKCTOCS researchers continued to follow up the participants on the trial until 2021. But there was still not enough evidence to show that it will save the lives of women who developed ovarian cancer. This means that this screening method is not effective in preventing women from dying from ovarian cancer.

UKCTOCS is run by the Gynaecological Cancer Research Centre at University College London and is funded by the Medical Research Council, Cancer Research UK and the National Health Service. You can find details of the trial at: [www.thelancet.com/article/S0140-6736\(21\)00731-5/fulltext](http://www.thelancet.com/article/S0140-6736(21)00731-5/fulltext).

The UK Familial Ovarian Cancer Screening Study (UKFOCSS)

This was a national study to assess and improve screening in those with a strong family history of ovarian cancer. The study recruited 4000 participants at increased risk of developing ovarian cancer. They had a CA125 blood test done every four months and a yearly ultrasound scan.

The UKFOCSS results were published in February 2017. They showed that screening was effective at detecting ovarian cancer before it showed symptoms.

Those being screened who were detected as having ovarian cancer were less likely to have advanced cancer. Their cancers were more likely to be able to be removed completely by surgery, which is known to prolong lives.

Preventative surgery

As an alternative to screening, doctors may offer preventative surgery to remove both the fallopian tubes and ovaries in people at high risk of developing ovarian cancer.

This is usually keyhole surgery, and removing both the ovaries will lead to menopause.

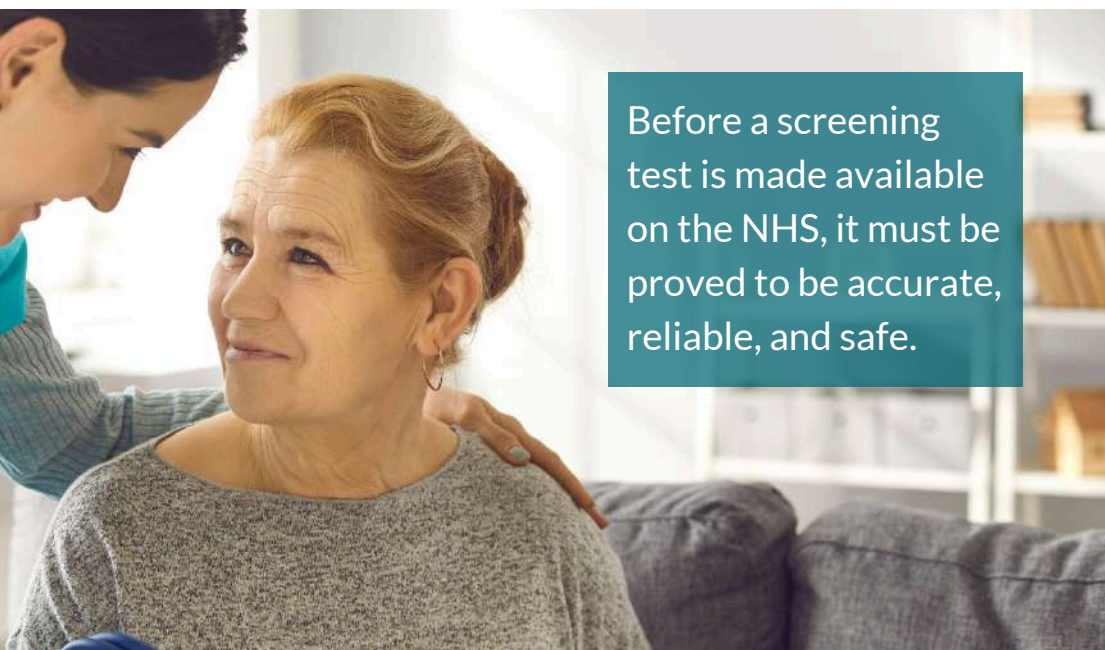
There are on-going clinical studies looking at the long-term benefit of offering preventative surgery to those at high risk of developing ovarian cancer.

Screening may have a role for those who are not yet ready to have preventative surgery. There are plans to trial this kind of screening as an NHS service to see if it is cost-effective. You can find more details at: www.ascopubs.org/doi/full/10.1200/JCO.2016.69.9330

The Prostate, Lung, Colorectal and Ovarian (PLCO) cancer screening trial

This large US randomised, controlled trial used yearly CA125 tests and ultrasound to screen 39,000 participants from the general population for ovarian cancer.

The trial results were published in 2011. It showed that yearly CA125 tests with ultrasound did not save lives and was associated with complications from surgery to remove the ovaries when cancer was suspected. So, this screening method did not prevent women from dying from ovarian cancer, and it exposed them to the risk of unnecessary surgery.



Before a screening test is made available on the NHS, it must be proved to be accurate, reliable, and safe.

Who could benefit from screening?

Those under 50 with no family history

If you are under 50 and have no family history of ovarian cancer or breast cancer, your risk of ovarian cancer is small. The risk of a false-positive screening result is high. So screening is not recommended if you are in this group.

Those over 50 with no family history

There is currently no evidence that screening is of value to people in this age group, and there are disadvantages associated with screening. So routine screening is not currently recommended.

Those with a weak family history

Many people in this group will have one close relative who has developed ovarian cancer and may be anxious about their own risk.

If you are in this group, your risk is generally only slightly increased, and the value of screening is uncertain. However, your risk may be increased if you have a weak family history and come from an Ashkenazi Jewish family. These families have a higher incidence of BRCA gene changes which is described below.

If you have concerns about your level of risk, speak to your GP. They can refer you to your local cancer genetics centre for advice and counselling.

Those with a strong family history

- If two or more close relatives have had ovarian cancer.
- You have one relative who has had ovarian cancer and another who has developed breast cancer aged under 50.
- You have a relative who has developed ovarian cancer and two others who have had breast cancer aged under 60.

A strong family history may indicate that a changed gene is being inherited which can increase the risk of ovarian cancer.

This may be the BRCA (breast cancer) gene which can carry changes that increase risk of breast cancer, ovarian cancer, prostate cancer and pancreatic cancers. It can be carried by males and females.

If you suspect that you may have a changed BRCA gene (described as being BRCA positive) you can ask your GP to arrange a test.

Other inherited gene changes can also increase the risk of ovarian cancer. This includes those which cause Lynch syndrome which can increase the risk of cancers such as ovarian, womb and bowel cancer.

Everyone diagnosed with a high-grade non-mucinous ovarian cancer, or with a strong family history, should be offered genetic testing and counselling.

See more information about ovarian cancer and genetic risk here:

- www.ovarian.org.uk/ovarian-cancer/brca
- <https://patientinfolibrary.royalmarsden.nhs.uk/brca1brac2>
- <https://patientinfolibrary.royalmarsden.nhs.uk/lynchsyndrome>

We welcome your feedback on this booklet. Please email ovacome@ovacome.org.uk or call 0800 008 7054. If you would like to discuss anything about ovarian cancer, please phone our support line on 0800 008 7054 Monday to Friday between 10am and 5pm. You can also visit our website at www.ovacome.org.uk. This is one of a series of information booklets produced by Ovacome. You can see them here: ovacome.org.uk/information.

Reviewed by: Dr Jason Yap Associate Clinical Professor and Consultant Gynaecological Cancer Surgeon, Institute of Cancer and Genomic Sciences, University of Birmingham.

Disclaimer

Ovacome booklets provide information and support. We make every effort to ensure the accuracy and reliability of the information at the time of publication. The information we give is not a substitute for professional medical care. If you suspect you have cancer, you should consult your doctor as quickly as possible. Ovacome cannot accept any liability for any inaccuracy in linked sources.

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Support line: 0800 008 7054
Office phone: 0207 299 6654
Website: www.ovacome.org.uk
Email: ovacome@ovacome.org.uk

Ovacome is here for anyone affected by ovarian cancer with free support, information and community when it's needed most. We receive no government funding, so everything we do is powered by people like you. If you can, please consider donating today. Scan the QR code or visit:

www.ovacome.org.uk/donate



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