

Briefing for the Public Petitions Committee

Petition Number: [PE1779](#)

Main Petitioner: Denise Hooper

Subject: Reducing the Risk of Ovarian Cancer

Calls on the Parliament to urge the Scottish Government to raise public awareness:

- of the importance of the CA125 blood test to help detect ovarian cancer;
- and that endometriosis can cause an increased risk of ovarian cancer.

Background

NHS Inform say that:

“In the UK, around 7,100 women are diagnosed with ovarian cancer each year.

It's the fifth most common cancer among women after [breast cancer](#), [bowel cancer](#), [lung cancer](#) and [cancer of the uterus \(womb\)](#).

Ovarian cancer is most common in women who have been through the [menopause](#) (usually over the age of 50), although it can affect women of any age.

As the [symptoms of ovarian cancer](#) can be similar to those of other conditions, it can be difficult to recognise. However, there are early symptoms to look out for, such as persistent bloating, pain in the pelvis and lower stomach, and difficulty eating.

The ovaries are a pair of small organs in the female reproductive system that contain and release an egg once a month. This is known as ovulation.

[Different types of ovarian cancer](#) affect different parts of the ovaries. Epithelial ovarian cancer, which affects the surface layers of the ovary, is the most common type.

The exact cause of ovarian cancer is unknown, but certain things are thought to increase a woman's risk of developing the condition, such as

age, the number of eggs the ovaries release and whether someone in your family has had ovarian or breast cancer in the past. However, only 1 in 10 cases of ovarian cancer has a genetic link.

Overall, 72 out of every 100 women (72%) will live for at least one year after being diagnosed with ovarian cancer. Around 46 out of 100 (46%) women will live for at least five years, and about 35 out of 100 (35%) will live for at least 10 years. However, women with advanced ovarian cancer have a poorer survival rate.”

Ovarian cancer is often detected at a late stage, meaning that 5-year survival rates can be very low (4% of those with stage 4¹ cancer)

According to NHS Scotland Information Services Division (ISD), [ovarian cancer was the sixth most common cancer in women](#) in 2017, and there were 603 cases registered (compared with 4706 cases of breast cancer, which is the most common cancer in women). ISD have produced data in graphic format, covering a range of topics such as incidence, trends and how incidence and mortality link to deprivation.

Endometriosis and ovarian cancer

[Endometriosis](#) is a common condition where tissue that behaves like the lining of the womb (the endometrium) is found outside the womb. These pieces of tissue can be found in many different areas of the body, including:

- the ovaries and fallopian tubes
- the lining of the inside of the abdomen
- the bowel or bladder

The condition is estimated to affect around 2 million women in the UK. Most of them are diagnosed between the ages of 25 and 40.

Endometriosis is a debilitating, painful long-term/chronic condition causing varied symptoms depending on where the tissue is.

Symptoms include:

- painful and/or heavy periods
- pain in the lower abdomen, pelvis or lower back
- pain during and after sex
- bleeding between periods
- difficulty getting pregnant
- persistent exhaustion and tiredness
- discomfort when going to the toilet
- rectal bleeding

¹ See <https://www.cancerresearchuk.org/about-cancer/what-is-cancer/stages-of-cancer?qclid=CPW9i7jLzuYCFcJCGwod7awO5w&qclsrc=ds#what>

- coughing blood – in rare cases when the endometriosis tissue is in the lung

Over a number of years, studies have suggested a link between gynaecological cancers², particularly ovarian cancer, and endometriosis. A number of reviews of the research have been carried out to find out if there is a link, and the circumstances where there might be any causal link with any particular form of ovarian cancer. Up until about two years ago, the conclusions don't appear to have been clear. However, [an integrative review of the research](#) was carried out in 2017, which suggested that there appeared to be a link with some types of epithelial ovarian cancer. [The Lancet published correspondence](#) in the same year, cautioning that any association between the two conditions was very limited:

“In the general population, it is estimated that one woman in 76 (1.31%) will develop ovarian cancer in her lifetime. Considering the relative risks calculated from meta-analyses of endometriosis and ovarian cancer (as high as 1.42), the lifetime risk of ovarian cancer among women with endometriosis is 1.80%—fewer than two women in 100. This small increase in absolute risk should thus reassure women with endometriosis that their lifetime ovarian cancer risk is quite low and, in absolute risk scales, is only negligibly different from women without endometriosis...”

The letter, from Marina Kvaskoff and Andrew W Horne³, goes on to highlight advice and reassurance that should be given to women with endometriosis who fear a link with ovarian cancer, saying that fewer than 2% of women with endometriosis will go on to develop ovarian cancer.

Genetic predisposition to ovarian cancer

As is the case with a number of cancers, such as breast, colorectal and prostate cancer, ovarian cancer can also run in families.

The genetic tests carried out to identify a higher risk of breast cancer (Breast Cancer gene 1 and 2 tests - [BRCA-1 and BRCA-2](#)) can also identify a higher risk of ovarian cancer.

According to [Lab Tests on-line](#), a national website produced through a collaboration of professional societies representing medical laboratories in the UK:

“The most useful prediction of risk from a BRCA1/2 test in an unaffected person is when a BRCA1/2 mutation has already been found in a relative with breast or ovarian cancer. Without this

² A search was carried out for peer reviewed research linking endometriosis with ovarian cancers which produced a number of results.

³ <https://www.ed.ac.uk/centre-reproductive-health/professor-andrew-horne>
<https://translate.google.com/translate?hl=en&sl=fr&u=https://expertes.fr/expertes/69467-marina-kvaskoff&prev=search>

information, a negative BRCA1/2 test result is often not very informative. There are therefore two types of BRCA1/2 testing; 'diagnostic' and 'predictive' testing.

Diagnostic BRCA1/2 testing. This test is done in someone who has had a breast or ovarian cancer, usually in the context of a strong family history. It can give you information about chances of further cancers and can provide family members with the information to have a predictive test.

Predictive BRCA1/2 testing. This test is done in an unaffected relative of someone who is known to have a BRCA1/2 gene mutation. If you are a child or sibling of this person there will usually be a 50:50 (1 in 2 or 50% chance) that you have, or have not, inherited the mutation.

Such testing may be useful to help you decide whether to take steps that may prevent breast or ovarian cancer from developing, or may pick it up at an early at a more treatable stage. There are a complex range of options available, ranging from more frequent mammograms to surgical removal of the organs at risk and you should discuss these in detail with a clinical genetics professional before deciding whether testing would be helpful or right for you. Your GP can refer you to your local clinical genetics service.”

So, BRCA testing is only informative when there is a known family history of breast or ovarian cancer, as a predictive test and to inform preventative options for family members of sufferers. It is not a primary diagnostic test for ovarian cancer.

National Guidance for diagnosis and treatment

The Scottish Intercollegiate Guidance Network (SIGN) is the national body that publishes evidence-based guidance for clinicians on a wide range of conditions and illnesses, including the most common type of ovarian cancer. Evidence is rated for robustness for each element of the guidance, from diagnosis to treatment and management. [SIGN 135 • Management of epithelial ovarian cancer](#) (link to 'quick reference guide') was revised in November 2018⁴. In epithelial ovarian cancer the cancer starts in the cells that cover the surface of the ovary. On diagnosis the guidance states:

“In women presenting in general practice with one or more symptoms of abdominal distension or bloating with or without abdominal pain, feeling full quickly, difficulty eating, or urinary symptoms, of less than 12 months duration and occurring more than 12 times per month a diagnosis of ovarian cancer should be considered.

⁴ SIGN's partner organisation for England and Wales is the National Institute for Health and Care Excellence (NICE), which also produces guidance, including on ovarian cancer: <https://pathways.nice.org.uk/pathways/ovarian-cancer>

CA125 blood serum level should be measured and urgent pelvic ultrasound carried out in women with persistent abdominal distension or feeling full and/or loss of appetite or pelvic or abdominal pain or increased urinary urgency and/or frequency (particularly if occurring more than 12 times per month and especially if she is over 50).

If symptoms persist or worsen despite normal CA125 and a negative ultrasound scan, refer to secondary care.”

CA125 blood test

CA 125 is a protein often found on the surface of ovarian cancer cells and in some normal tissues. It can indicate ovarian cancer. However, CA 125 levels may also be high in other types of non-cancerous conditions, including fibroids, endometriosis, menstruation, pregnancy, and pelvic inflammatory disease.

The [CA125 levels are measured using a simple blood test.](#)

Not all ovarian cancers have raised levels of CA 125, but increased levels have been found in about 80% of women with ovarian cancer.

Because a number of other conditions lead to an increase in CA125 levels, it is not an appropriate test for population-wide screening for ovarian cancer.

Screening for ovarian cancer

Population level screening programmes are decided by a [UK-wide National Screening Committee](#) comprising representatives from all four UK countries. The Committee publishes an annual report of recommendations. Around ten conditions a year are considered by the Committee and a review of the evidence from research is undertaken and recommendations made. Ovarian cancer was considered by the Committee in 2016.

Ovarian cancer	
The condition	Ovarian cancer is the 6th most common cancer among women in the UK. It is often diagnosed when the disease has spread from the ovaries and the likelihood of being cured is reduced. The aim of a screening programme would be to find and treat the cancer at an earlier stage to improve outcomes and, in particular, survival rates..
UK NSC recommendation	The UK NSC recommends that screening should not be offered except in the context of the Medical Research Council randomised controlled trial. 
Reasons	The debate about screening is dominated by the UK Clinical Trial of Ovarian Cancer Screening (UKCTOCS). This is a randomised controlled trial with the primary aim of establishing the impact of screening for ovarian cancer on mortality. The trial outcomes were published in 2015 and did not demonstrate a reduction in mortality after a mean follow-up period of 11.1 years. Consequently it was not possible to recommend screening and longer term follow-up is being undertaken. The committee will continue to monitor the outcomes of the UKCTOCS trial to see whether a reduction in mortality from screening is achieved in the longer term.
Next review due	2019 to 2020
More information	legacy.screening.phe.org.uk/ovariancancer

The reasons why CA125 blood testing is not an appropriate screening method are given above, as is information on the genetic testing available for those at high risk, with BRCA1 and 2 tests. According to NHS Inform:

“There are methods of screening for ovarian cancer but, currently, they haven't been fully tested. Screening is only available for women who are at high risk of developing the condition due to a strong family history or inheritance of a particular faulty gene. Clinical trials in the UK are currently being carried out to assess the effectiveness of screening in high-risk women and in the general population.”

[Cervical screening](#), which is a national screening service in Scotland cannot detect ovarian cancer.

Screening for ovarian cancer has been considered for a number of years. [A long-term study by the United Kingdom Collaborative Trial of Ovarian Cancer Screening \(UKCTOCS\)](#) started with a cohort of around 200,000 women in 2001. [The initial phase was completed in 2016, and a report of the follow-up study was due to be published late in 2019.](#) It is this study which will form the basis of a decision on nationwide screening by the UK Screening Committee in the coming year.

The [NHS reported on the study in 2009](#) on the randomised controlled trial looking at the success of combined screening by ultrasound and blood testing. It was found that a number of women were referred for surgery in the screened groups which proved unnecessary because the abnormalities detected via screening were not malignant. Also, as shown above, screening did not lead to a significant fall in mortality between the screened and not screened women. However, in 2009, the report appears to suggest that screening does have an impact on outcomes. As the study has progressed however, the evidence suggests that screening does not significantly impact on mortality. According to the Eve Appeal's web page about the project, “The early results suggested that approximately 15 ovarian cancer deaths could be prevented for every 10,000 women who attend a screening programme that involves annual blood tests for between seven to 11 years.” It also notes that for every three abnormal screens, two women underwent unnecessary surgery, that carries its own complications, and no cancer was present in these women.

Unnecessary treatment, and the attendant anxiety has to be set against timely diagnosis from screening, and is the balance that has to be struck when any population-wide screening programme is considered.

[Public Health England commissioned a cost-effectiveness study in 2016](#), after the initial phase (due to be reviewed in 2020), which concluded that population level screening was not recommended because of the lack of significant effect on mortality.

Scottish Government Action

The Scottish Government launched '[Beating Cancer: Ambition and Action](#)' in 2016 to improve early detection and outcomes for people diagnosed with cancer.

Two key performance targets relate to cancer diagnosis and treatment:

From 2011, the cancer waiting time targets, as decided by the Scottish Government, are as follows:

- 62-day target from receipt of referral to treatment for all cancers. This applied to each of the following groups:
 - any patients urgently referred with a suspicion of cancer by their primary care clinician (for example GP) or dentist
 - any screened-positive patients who are referred through a national cancer screening programme (breast, colorectal or cervical)
 - any direct referral to hospital where the signs and symptoms are consistent with the cancer diagnosed as per the Scottish Referral Guidelines (for example self-referral to A&E)
- 31-day target from decision to treat until first treatment for all cancers, no matter how patients were referred. For breast cancer, this replaced the previous 31-day diagnosis to treatment target.

([source ISD Scotland](#))

In May 2017, the [Scottish Cancer Registry](#) was established to bring together all the national data on cancer incidence to enable healthcare professionals to access a broad range of cancer related information and intelligence from across NHS Scotland to support cancer services and enable improvements in patient outcomes for those affected by cancer. Since May 2019, data and information has been presented in a '[dashboard](#)' format in domains including early diagnosis, treatment, prevention and management.

As part of this work, NHS Information Services Division produce reports on particular cancers. In February 2018, ISD published a [report on the Quality Performance Indicators](#) (QPIs) for people diagnosed with ovarian cancer between 2013 and 2016.

Data is collated from health boards through three regional cancer research networks. Performance is measured against nine 'quality performance indicators' covering actions from the recording of risk of malignancy, through discussion by a multi-disciplinary team on treatment options, to treatment itself. The report discusses performance against targets for each QPI.

The Scottish Government undertook a [consultation to review the QPIs](#) in December/January 2017/18

Scottish Parliament Action

[Question S5W-17562: Iain Gray, East Lothian, Scottish Labour, Date Lodged: 29/06/2018](#)

To ask the Scottish Government what progress it has made in implementing the recommendations in Pathfinder Scotland's report, [Transforming futures for women with ovarian cancer](#), in particular, in relation to the first recommended action in relation to the inclusion of ovarian cancer in a Detect Cancer Early awareness campaign.

Answered by Jeane Freeman (20/07/2018):

A new Detect Cancer Early campaign, relevant to all tumours, is due to launch later this year to reduce fear of cancer and empower those with a worry or concern to take action. An options appraisal – to review new evidence and consider the addition of a new tumour group to Detect Cancer Early is also underway with clinicians, charities and patients across Scotland.

The report also listed two other key actions for Scotland. One was 'A review of the implementation of SIGN 'Management of epithelial ovarian cancer: a national clinical guideline (135)' to ensure this has been rolled out fully and to evaluate its impact'. With regards to this, regions have agreed clinical management guidelines and treatment protocols in place to underpin the care and treatment for patients diagnosed with epithelial ovarian cancer that take account of current clinical evidence and best practice guidance. Performance against nationally agreed quality performance indicators is reviewed annually. Work is underway to further analyse this data.

The third key action was 'NHS Scotland to ensure all women with ovarian cancer are aware of where to go for support, including counselling.' In relation to this, GP and other members of the multidisciplinary team are expected to signpost/refer patients to appropriate sources of support. We have also committed to deploying 250 community links workers in practices who work directly with patients to help them navigate and engage with wider services including cancer support services. In addition, NHS Scotland works in partnership with Macmillan Cancer Support, who deliver Improving the Cancer Journey programme, which seeks to ensure people with cancer have access to all the support services and information they are entitled to.

MSP, Iain Gray [also asked about the report](#) in June 2017.

A [number of MSPs have raised Parliamentary Motions](#) in support of, and to raise awareness of ovarian cancer.

[Cross Party Group on Women's Health](#) (convener is Monica Lennon MSP)

Cross Party Group on Cancer (convener is Miles Briggs MSP)

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8 January 2020

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