



Womb Cancer Consensus Statement



Foreword

I would like to congratulate The Eve Appeal and the National Forum of Gynaecological Oncology Nurses (NFGON) on their combined efforts in producing this Consensus Statement and Key Messages.

I particularly welcome the work of this unique partnership because it aims to raise awareness of the signs and symptoms of womb cancer. Womb cancer is not well known; its incidence is growing and forecast to increase still further over the next decade.

Driving early diagnosis for all cancers is a key part of our strategy for pushing up survival rates in the UK. The work of organisations like The Eve Appeal and NFGON is playing an increasingly important role in informing women and encouraging them to visit their GP when they spot signs and symptoms of gynaecological cancers.

My congratulations again.

A handwritten signature in black ink, which appears to read 'Mike Richards'.

Professor (Sir) Mike Richards CBE

National Clinical Director for Cancer

The Womb Cancer Consensus Statement

This document is concerned with womb cancer (cancer of the uterus) which arises in the womb lining (endometrium) and does not contain specific information about rarer cancers of the womb such as sarcomas.

The document comprises a consensus statement for health professionals and key messages for women. It is one element of the Womb Cancer Awareness Project; a joint initiative between gynaecological cancer research charity The Eve Appeal and the National Forum for Gynaecological Oncology Nurses (NFGON). The work has been undertaken jointly with input from an expert panel with health professionals, researchers and lay membership from the specialist field of gynaecological cancer and from primary care.

Background information

- Womb cancer is the most common gynaecological cancer in the UK. Each year more than 7,500 cases are diagnosed in the UK and about 1,700 women die from the disease¹
- There is likely to be a 33-53% increase in the incidence of womb cancer by 2020, as a result of lifestyle changes, which include an increased rate of obesity (over a third of womb cancers are thought to be related to being overweight, i.e. with a Body Mass Index of more than 25)^{2,3}
- Survival is strongly associated with the stage at diagnosis. Of those women found to be stage 1 at diagnosis, over 80% will be alive in five years' time. The five-year survival for stage 2 womb cancer is 70-80%. Stage 3 cancer has a five-year survival rate of 40-50%, whilst stage 4 cancer has a five-year survival rate of only 20-30%¹
- Survival is also associated with tumour type (type 1 oestrogen related and type 2 non-oestrogen related), as well as stage of disease at diagnosis. Early stage, low grade type 1 tumours have an excellent prognosis. However, type 2 tumours and high grade type 1 tumours account for approximately 10-20% of womb cancers and are associated with significantly poorer prognosis, even for early stage disease^{1,4,5}
- Older women have a reduced five-year survival rate from womb cancer and are more likely to have a type 2 cancer. Women between the ages of 80-99 years have just over 50% five year survival, whereas women aged 50-59 years, who more commonly present with type 1 cancers, have a 85% chance of a five year survival from their cancer. The difference in five-year survival for elderly women with womb cancer is mainly due to their poorer one year survival from the cancer than younger women^{1,4,6}
- There are reported regional variations in five-year survival from womb cancer in England and Wales, which directly reflect regional levels of deprivation. A 4.5% variation in five year survival was found between those most deprived and those least deprived^{1,7,8}
- The United Kingdom has previously been reported as having poorer five year survival rates than other European countries; recent analysis has suggested that earlier detection and management of womb cancer may bring England in line with average European rates of survival^{9,10,11}

The above information only relates to women who do not have a specific high risk for womb cancer such as a genetic predisposition i.e. Lynch Syndrome.¹² An estimated 5% of womb cancers may be attributed to an inherited predisposition to cancer and 1 in 6 of these genetic predisposition womb cancers develop before the age of 40 years. There are nationally agreed guidelines for the referral of women and their families to regional genetics services.^{12,29}

What we know and agree on

- There is little public awareness about the signs and symptoms of gynaecological cancers^{13,14}
- There have been recent awareness campaigns on the signs and symptoms of ovarian and cervical cancers, but this has not yet been replicated for womb cancer
- Lack of public awareness about womb cancer is reflected in the absence of a dedicated national charity providing supportive care and information solely on womb cancer. The Eve Appeal was the first national charity to commit to raising awareness of womb cancer
- Obesity and social class are strongly related, especially amongst women. Women from lower socio-economic groups are more likely to be obese and less likely to participate in physical activity, a trend which is predicted to continue^{15,16}
- Older women and those from more deprived communities currently have lower chances of living for five years or more after their diagnosis with womb cancer. The predicted rise in the total number of women who develop womb cancer each year is therefore likely to lead to an increase in the total number of women from these communities with womb cancer
- Once women present at their GP, there are clear NICE (2005) guidelines on the urgent suspected gynaecological cancer referral process from primary care¹⁷
- Diagnosis of this cancer relies upon invasive investigations (trans-vaginal ultrasound and womb biopsy with or without hysteroscopy), which can be carried out within the outpatient setting for the majority of women

Early signs and symptoms:

- Post-menopausal vaginal bleeding, in women not taking hormone replacement therapy^{17,18}
- Post-menopausal vaginal bleeding, which persists for four to six weeks after stopping hormone replacement therapy^{17,18}
- Intermenstrual vaginal bleeding^{17,18}

Risk factors:

Womb cancer can occur in a broad range of women of varying ages who do not have obvious risk factors. It is important that all women with intermenstrual bleeding or post-menopausal bleeding have their symptoms fully investigated.

- Age: approximately 93% of womb cancers occur in women over the age of 50, with a peak age of diagnosis between 60-65 years. Each year approximately 25 women under the age of 35 years and over 500 women under the age of 50 will develop womb cancer^{1,18}
- Being overweight: a Body Mass Index of 25 or above^{18,19,20}
- Excess exposure to oestrogen unopposed by progestagens, associated with “anovular” menstrual cycles for women who do not ovulate regularly e.g. polycystic ovary syndrome (PCOS) and exogenous unopposed oestrogen (e.g. oestrogen-alone HRT and vaginal oestrogen preparations)^{21,22}
- Type 1 and 2 diabetes^{18,23}

Factors which may reduce the risk:

- Maintenance of a BMI under 25 and increased physical activity^{19,20}
- Prevention of type 2 diabetes²³
- Use of the oral combined contraceptive pill²⁴
- Higher number of pregnancies^{25,26}

Factors which may reduce the risk in the higher risk population:

(i.e. BMI above 25, PCOS or prolonged exposure to unopposed oestrogens)

- Progesterone protection of the endometrium (may include depo progesterone contraception e.g. Mirena IUD)²¹
- Early detection and management of a thickened abnormal womb lining (atypical endometrial hyperplasia)

What we don't know

- Type 1 (oestrogen-related) and type 2 (non-oestrogen-related) tumours have different genetic profiles. We need to find out more about the key genes involved in womb cancer so that we can understand mechanisms of causation, progression and development of metastases and develop biomarkers of prognosis and therapeutic benefit²⁷
- The benefit of screening asymptomatic women including women with a high risk for developing womb cancer, such as Lynch Syndrome^{12,28,29}
- The best way to target key messages and influence health behaviours for the prevention and early detection of womb cancers: to include older women, those from areas of social deprivation and those who are overweight
- If greater access to local community assessment in areas of social deprivation or within communities which commonly have inequalities in healthcare access would lead to an improvement in early detection and prevention

The way forward

In order to prevent as many deaths as possible from womb cancer in the future, there is a need to raise awareness about its prevention and early detection. This is especially important at a time when:

- We are seeing significant increases in the incidence of this cancer, which are predicted to continue rising over the next 20 years
- There are inequalities in survival amongst certain communities
- UK survival rates are still reported as lower than the European average

Further research is required to:

- Investigate the key genes involved in womb cancer so that we can understand mechanisms of causation, progression and development of metastases and develop biomarkers of prognosis and therapeutic benefit
- Determine the value of screening for womb cancer including its value in women with a genetic risk of womb cancer
- Assess impact of awareness raising campaigns on the early detection and prevention of womb cancer
- Evaluate the impact of weight loss and increased physical activity amongst women on the incidence of womb cancer
- Test and evaluate service developments which aim to improve access to rapid diagnostic services

All agree the need to:

- Push womb cancer up media, policy and research agendas
- Raise awareness about the signs and symptoms of womb cancer amongst public and primary healthcare practitioners
- Continue to work together to improve the prevention, early detection and management of women at risk from or diagnosed with womb cancer

Key messages for women about womb cancer (cancer of the uterus)

These key messages are about cancer of the lining of the womb. This is often called endometrial cancer, womb cancer or cancer of the uterus. Womb cancer is different from cervical cancer which occurs at the entrance to the womb.

Womb cancer is the fourth most common cancer in women in the UK and is on the increase each year due to changes in our lifestyles. Over 7,500 women are diagnosed every year in the UK.

Womb cancer is almost always curable if caught at an early stage

Cervical screening tests (previously known as smear tests) are not done to detect womb cancer

The key early signs and symptoms of womb cancer are:

- Vaginal bleeding after the menopause
- Vaginal bleeding between periods

If you have any abnormal bleeding, tell your GP straight away

If this abnormal bleeding continues or worsens then return to your GP and explain this to them

The leading risk factors for getting womb cancer are:

- Being over 50 years old
- Being overweight. The risk of womb cancer increases significantly in women with a BMI (Body Mass Index) of more than 25
- Having diabetes

The following actions may reduce the risk of developing womb cancer:

- Maintaining a healthy physically active lifestyle to prevent becoming overweight (a Body Mass Index greater than 25) and prevent the development of type 2 diabetes
- Use of a combined oral contraceptive (COC)

Remember early diagnosis can save lives.

Expert Panel

This Consensus Statement and Key Messages for Women have been prepared with the help and guidance of members of the Expert Panel who were recruited specially for this project.

Our thanks go to all the members for their time.

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About The Eve Appeal

The Eve Appeal fundraises for world-leading research into gynaecological cancers and raises awareness of the diseases.

Since its public launch in 2005 the charity has donated nearly £4 million to the Gynaecological Cancer Research Centre at UCL.

Every year in the UK, 18,000 women are diagnosed and nearly 7,500 women die from a gynaecological cancer, yet awareness and funding of gynaecological cancers remains low.

The Eve Appeal is the first national charity to commit to raising awareness of the signs and symptoms of womb cancer.

The research The Eve Appeal supports is complicated and challenging but its vision is simple:

A future where fewer women develop and more women survive gynaecological cancers

To find out more about the charity or support its work please visit www.eveappeal.org.uk or call the office on 0207 299 4430.

About the National Forum of Gynaecological Oncology Nurses (NFGON)

NFGON is available to all nurses and health professionals with any level of interest or expertise in gynaecological oncology. It is affiliated with the British Gynaecological Cancer Society.

About the Womb Cancer Awareness Project

The Womb Cancer Awareness Project is a joint initiative between gynaecological cancer research charity The Eve Appeal and the National Forum for Gynaecological Oncology Nurses (NFGON).

Key project aims are to push womb cancer up the media, policy and research agenda and to build awareness of signs and symptoms of womb cancer amongst women.

This consensus statement and key messages for women, produced with input from an expert panel, represents the first step in producing information to disseminate.

For further information about the initiative please contact nfgon@eveappeal.org.uk



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The Womb Cancer Awareness Project is a joint initiative between The Eve Appeal and The National Forum for Gynaecological Oncology Nurses. Its vision is one of a world where fewer women develop, and more women survive, womb cancer.

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