

# Ovarian Cancer UK Consensus Statement



the  
**eve**  
appeal

in partnership with

**ovacome..**  
the ovarian cancer support network

---

# Ovarian Cancer UK Consensus Statement: Introduction



---

This Ovarian Cancer UK Consensus Statement has been developed following a meeting on ovarian cancer symptoms held at the UCL Institute for Women's Health conference in April 2008.

The meeting, organised by The Eve Appeal in partnership with patient support group Ovacome, was attended by leading clinicians, researchers, policy-makers, representatives from cancer charities and people affected by ovarian cancer.

The aim of this initiative is to provide a vital first step in the process of delivering the most up to date evidence based guidance to UK health professionals and women on which signs and symptoms to look out for, and what action to take.

In addition to setting out where there is agreement on evidence about signs and symptoms the Consensus Statement highlights gaps in the available research in this area and sets out further action that could be taken to improve our knowledge and practice. The Consensus Statement has already informed a Department of Health initiative to develop ovarian cancer key messages.

---

# Ovarian Cancer UK

# Consensus Statement

---

## Background information

- Ovarian cancer is the most common gynaecological cancer in the UK. Each year, more than 6,600 cases of ovarian cancer are diagnosed and about 4,400 women die from the disease. Ovarian cancer accounts for about 6% of all female deaths from cancer. <sup>i</sup>
- Survival is strongly associated with stage at diagnosis. Figures that are available suggest that 9 out of 10 women (90%) diagnosed with stage 1A and 1B ovarian cancer will be alive in 5 years time (the five-year survival rate). For stage 2 cancer, between 6 and 7 out of 10 women (60 to 70%) will be alive 5 years later. The five-year survival rate for stage 3 is between 15 and 35 out of every 100 women (15-35%) and for stage 4 is between 5-14 out of 100 women (5-14%). <sup>ii</sup>
- The older a woman is at diagnosis, the lower her 5-year survival rate. Women aged 15-39 at diagnosis have a 5-year survival rate of nearly 70% compared to 12% for women diagnosed in their 80's. Women under 50 are more likely to be diagnosed with local disease and women over 65 are more likely to be diagnosed with distant metastases. The highest incidence rates are for women aged 65 and older. <sup>iii</sup>
- The UK has poorer survival rates than many other European countries <sup>iv</sup> although reasons for this are complex.
- A 10-year study of screening for ovarian cancer (UKCTOCS) is currently underway. The purpose of this study is to determine whether transvaginal ultrasound or serum CA125 testing will detect ovarian cancer at an early stage when treatment is more effective and therefore reduce the number of deaths due to the disease.
- The above information applies to the general population and not to women who are high risk, i.e. who have a faulty BRCA1 or BRCA2 gene, who have an estimated lifetime risk of developing ovarian cancer of approximately 50%. <sup>v</sup>

## What we know and agree on

- Awareness of ovarian cancer is very low. Only 16% of women surveyed by Dr Foster in 2007 were aware of ovarian cancer. Two-thirds were not able to cite any symptoms of ovarian cancer or said they did not know or were not able to mention any risks associated with ovarian cancer. <sup>vi</sup>

- Information about ovarian cancer symptoms currently provided to the public, for example by cancer charities and other health organisations, is often inconsistent.
- Ovarian cancer has in the past frequently been described as 'silent' - however, women with ovarian cancer often have a range of common symptoms. <sup>vii</sup>
- Women often follow convoluted referral pathways before being correctly diagnosed, with 50% of women not being referred directly to gynaecological cancer clinics. This is due to both women and GPs failing to recognise the presenting symptoms of ovarian cancer. <sup>viii, ix</sup>
- Preliminary evidence currently available shows that the following symptoms are frequent in patients who go on to be diagnosed with ovarian cancer: <sup>ix, x, xi, xii, xiii</sup>
  - Pelvic and abdominal pain
  - Increased abdominal size/persistent bloating
  - Difficulty eating and feeling full
- Evidence also shows that:
  - it is the frequency, persistency, severity and new onset of these symptoms that may help to differentiate between those who are experiencing symptoms related to ovarian cancer and those who are not. <sup>x, xii</sup>
  - symptoms may be present for a median of 12 months prior to diagnosis. <sup>x</sup>
  - symptoms can occur in cancers which are clinically diagnosed at an early stage. <sup>ix, xiii</sup>
- There is encouraging preliminary evidence that suggests that the use of a symptom index may help to distinguish people with cancer from healthy women. <sup>xii</sup>
- A proportion of healthy women will also have these symptoms and this could lead to investigations, including surgery, that may be of no benefit to the woman and could potentially be of physical and/or psychological harm.
- Currently, some healthy women are already subjected to unnecessary investigations.
- Difficulties and/or delays in diagnosis are often a cause of distress for patients as well as health professionals.

## What we don't know

- Our understanding of the natural history of ovarian cancer is limited. For example, we don't know why some ovarian cancers spread beyond the ovaries at a very early time in their development whilst other tumors appear to remain confined to the ovaries (stage 1 disease) until the tumors have grown very large.
- Whether acting on ovarian cancer symptoms will improve survival rates or reduce the number of deaths.
- Why UK survival rates are lower than they are in many other European countries. For example, whether this is related to delays in diagnosis or other factors like better treatments.
- How awareness levels compare between the UK and other countries.
- We do not know with certainty how good symptoms are at detecting ovarian cancer and how frequent they are in women who don't have ovarian cancer. (However, recent studies have shown the majority of women with ovarian cancer, even those with early stage disease, have symptoms prior to diagnosis and that these symptoms cause women to seek medical care, which may allow for earlier detection.)<sup>ix x xiii</sup>
- What the effect of a symptom awareness campaign and index on the GP patient relationship would be – or what the impact of not having a symptom awareness campaign and index is. (For instance, it is not clear how many patients are at present being referred for investigation on the basis of anxiety or short-lived symptoms, and whether the adoption of a symptom diary, including length and persistence of symptoms, would result in fewer patients being referred inappropriately.)
- What the economic cost implications would be in terms of early detection and treatment versus unnecessary delays.

## The way forward

In order to reduce deaths from ovarian cancer we must continue to undertake research to improve our understanding of the natural history of ovarian cancer as well its prevention, treatment and cure.

There is also a need for high quality research to fill the many gaps in our knowledge about awareness of symptoms and measures that will improve early diagnosis as outlined above. This includes studies as follows:

- to help understand the potential to improve early detection through raising awareness about symptoms and the use of symptom indexes in primary care.
- prospective studies to evaluate and optimise strategies for the use of a symptom index in primary care.
- to provide more information about the impact of awareness raising campaigns – including studies that examine international experience in relation to the role of awareness levels and early detection.
- There are differences in views about whether we are ready for a large scale nationally funded programme on ovarian cancer symptoms and whether we should encourage women to use a symptom index score.
- Some believe that a symptom index should be used in clinical practice whilst others believe that it should only be used in the context of a properly designed research study.

## All agree on the need to:

- Increase awareness of current knowledge about ovarian cancer symptoms amongst primary healthcare professionals and to make sure that healthcare professionals are aware of what is not useful i.e. ensuring that there is an understanding of symptom awareness in the context of persistency, frequency and severity
- To continue to work together for the benefit of UK women.

- 
- <sup>i</sup> Cancer Research UK, (<http://www.info.cancerresearchuk.org/cancerstats/types/ovary/mortality>) accessed June 2008
- <sup>ii</sup> Cancer Research UK, (<http://www.cancerhelp.org.uk/help/default.asp?page=5449>) accessed July 2008
- <sup>iii</sup> Cancer Research UK, (<http://info.cancerresearchuk.org/cancerstats/types/ovary/survival/age>) accessed June 2008
- <sup>iv</sup> Berrino F, De Angelis R, Santb M, Rosso S, Lasota M.B, Coebergh J.W Santaquilani M. and the EURO CARE Working Group: Survival for eight major cancers and all cancers combined for European adults diagnosed in 1995-99: results of the EURO CARE-4 study, *Lancet Oncology* 2007, 8: 773-783.
- <sup>v</sup> Cancer Research UK, Cancer Research UK, (<http://info.cancerresearchuk.org/cancerstats/types/ovary/molecularbiologyandgenetics>) accessed June 2008
- <sup>vi</sup> Ovarian cancer action National Awareness Survey 2006/07, Dr Foster Healthcare Consultancy
- <sup>vii</sup> Bankhead C, Kehoe S, Austoker J. Symptoms associated with diagnosis of ovarian cancer: a systematic review. *BJOG* 2005;112:857-865.
- <sup>viii</sup> Chan K. Reducing Delays in Referrals. *Cancer Services Collaborative Service Improvement Guide: Ovarian Cancer*. London: NHS Modernisation Agency, 2001
- <sup>ix</sup> Goff BA, Manfel L, Muntz HG, Melancon CH. Ovarian carcinoma diagnosis: results of a national cancer survey. *Cancer* 2000; 89:2068-75.
- <sup>x</sup> Bankhead CR, Collins C, Stokes-Lampard H, Rose P, Wilson S, Clements A, Mant D, Kehoe S, Austoker J, Identifying Symptoms of ovarian cancer: a qualitative and quantitative study, *BJOG*, 2008: 115 (8); 1008-1014
- <sup>xi</sup> Ovarian Cancer in UKOPS interim analysis: preliminary results. As presented by Anita Lim at The Eve Appeal in partnership with patient support group, Ovacom, at the Ovarian Cancer Consensus Conference, London, April 8 2008.
- <sup>xii</sup> Goff BA, Mandel L.S., Drescher CW, Urban N, Gough S, Schurman KM, Patar J, Mahony BS, Andersen M, Development of an Ovarian Cancer Index: Possibilities for Earlier Detection *CANCER* 2007(2):221-7
- <sup>xiii</sup> Goff BA, Mandel LS, Melancon C, Muntz HG. Frequency of symptoms in ovarian cancer in women presenting to primary care clinics. *JAMA* 2004; 291(22): 2705-12



the  
eve  
appeal

in partnership with

ovacom...  
the ovarian cancer support network

---

# This Ovarian Cancer UK Consensus Statement has been developed and is supported by the following:

**Dr Clare Bankhead, DPhil, MSc, BSc,**

Cancer Research UK Primary Care Education Research Group

**Louise Bayne,** Director, Ovacom

**Professor Lesley Fallowfield,** Professor of Psycho-oncology at Brighton & Sussex Medical School, University of Sussex where she is Director of the Cancer Research UK Psychosocial Oncology Group

**Alex Ford,** Chief Executive, The Eve Appeal

**Professor Ian Jacobs,** Director UCL Elizabeth Garrett Anderson Institute for Women's Health

**Dr Sarah Jarvis,** Women's Health Spokesperson, Royal College of General Practitioners

**Dr Sean Kehoe,** Lead Consultant in Gynaecology, John Radcliffe Hospital and Senior Research Fellow, St Peter's College, Oxford

**Professor David Luesley,** Lawson-Tait Professor of Gynaecological Oncology, University of Birmingham, Honorary Consultant Gynaecology, City Hospital Trust, Birmingham

**Dr Josephine McHugo - MB, FRCR, FRCP, FRCPC,** Head of Diagnostic Imaging, Birmingham Women's Hospital, Honorary Clinical Senior Lecturer, Birmingham University

**Dr Usha Menon, MD, FRCOG,** Senior Lecturer/Consultant, Gynaecological Cancer Research Centre, UCL Elizabeth Garrett Institute for Women's Health

**Mr Andy Nordin,** Consultant Gynaecological Oncologist / Hon Senior Lecturer National Clinical Lead for Gynaecology: NHS Cancer Improvement

**Professor Mike Richards,** National Cancer Director

**Juliette Sim,** National Forum of Gynaecological Oncology Nurses

**Cancer Research UK**



As part of its ongoing support of The Eve Appeal Boots supported the Consensus Conference which started the process of developing the Ovarian Cancer UK Consensus Statement. The Eve Appeal in partnership with Ovacom is grateful for Boots support on this initiative.



the  
**eve**  
appeal

in partnership with

**ovacome**..  
the ovarian cancer support network

The Eve Appeal  
PO Box 5696  
London  
W1A 7AU

**Tel:** 020 7299 4430  
**Fax:** 020 7580 6248  
**Email:** [office@eveappeal.org.uk](mailto:office@eveappeal.org.uk)  
**Website:** [www.eveappeal.org.uk](http://www.eveappeal.org.uk)

Ovacome  
First Floor  
Butler House  
177-178, Tottenham Court Road  
London, W1T 7NY

**Supportline:** 0845 371 0554  
**Tel:** 020 7299 6654  
**Website:** [www.ovacome.org.uk](http://www.ovacome.org.uk)