



# Bridging the gap: Improving outcomes for women with ovarian cancer

Results from the Target Ovarian Cancer  
Pathfinder Study (2012)





“Target Ovarian Cancer is an extraordinary and impressive charity which in its short history has already made a dramatic impact on the profile of ovarian cancer in the United Kingdom and is making a very significant contribution in improving public awareness, early diagnosis and management of this disease.”

**Mr Andy Nordin FRCOG**

Clinical Advisor to the National Cancer Action Team & NHS Improvement, Chair of the National Group of Gynae Cancer Network Leads and Chair of the National Cancer Intelligence Network Gynaecology Site Specific Clinical Reference Group



Target Ovarian Cancer was named Overall Winner of the 2012 GSK IMPACT Awards run in partnership with The King's Fund for 'outstanding contribution to improving health'

“Target Ovarian Cancer is an incredibly professional organisation that has achieved a huge amount in just three years. The judges were particularly impressed with the impact it had had, which was far beyond what one would expect from the size of the organisation. It has moved ovarian cancer up GPs' agendas and provided them with the tools to better identify the disease. It is a shining example of what can be achieved in a short space of time.”

**Judging panel, 2012 GSK IMPACT Award**

Sir Christopher Gent, Chairman, GlaxoSmithKline plc;  
Professor Steve Field CBE, Deputy National Medical Director, NHS Commissioning Board;  
Gilly Green OBE, Head of UK Grants, Comic Relief;  
Sir Christopher Kelly, Chairman, The King's Fund;  
Peter Wanless CB, Chief Executive, Big Lottery Fund;  
Simon Bicknell, Senior Vice President, Ethics & Assurance, GlaxoSmithKline plc;  
Claire Dixon, VP Global Corporate Responsibility, GlaxoSmithKline plc

# Contents

---

Foreword	4
About the Pathfinder Study	6
1. The journey begins – awareness	8
2. Choosing the right road – challenges and opportunities in primary care	10
3. On the road – diagnosis and treatment	14
4. Clinical trials – perspectives of patients and clinicians	16
5. Living with ovarian cancer – emotional, practical and financial support needs	18
6. Professional perspectives	22
Ovarian cancer factfile	28
About Target Ovarian Cancer	29
Target Ovarian Cancer – free resources for women	30
References	31

To find out more visit  
[www.targetovariancancer.org.uk/pathfinder](http://www.targetovariancancer.org.uk/pathfinder)

# Foreword

---



**Almost a third (32%) of women with ovarian cancer in the United Kingdom are diagnosed in A&E, with devastating impact on one-year survival rates. This shocking statistic, released in late 2012 by the National Cancer Intelligence Network provides a stark and very timely reminder of the urgency and importance of work to improve the life chances of women with ovarian cancer.<sup>1</sup>**

The Government's own figures state that if we matched the best five-year survival rate for ovarian cancer in Europe, up to 500 women's lives would be saved each year. But we can go even further than this. By our own calculation, if we were able to replicate the progress seen in breast cancer over the last few decades, that figure would rise to 3,000 each year. Currently some 7,000 women are diagnosed each year with the disease, and 4,300 women lose their lives. The opportunity to radically alter outcomes for women with ovarian cancer, to bridge the gap between countries and other diseases, is clear.

Target Ovarian Cancer was formed in 2008, and to help us define our areas of work, and inform others working in the field, we launched the Target Ovarian Cancer Pathfinder Study. This on-going study tracks the experiences of those living or working with ovarian cancer in the UK with the purpose of identifying challenges and opportunities to improve survival and quality of life.

The first results were published in 2009, and as a result, we focused our work on three main areas:

- **Improving early diagnosis**
- **Finding new treatments**
- **Supporting women with ovarian cancer**

In addition the first study provided vital information to policy makers, politicians and professionals alike about the challenges and opportunities in ovarian cancer management. For example it provided the first evidence to the Department of Health that most GPs did not have direct access to urgent diagnostic scans, leading to the announcement of major investment in ultrasound in England.



---

Three years on, and the NHS in England is in the midst of a programme of change ‘so large, you can see it from space’.<sup>2</sup> We have seen an increasing focus on the early diagnosis of cancer, particularly from the Government through the Be Clear on Cancer campaigns and the Cancer Strategy, and now also from Scotland in their Detect Cancer Early programme. We also have an increasing wealth of data from bodies such as the National Cancer Intelligence Network (NCIN), that highlights the inequalities faced by women, not only within Europe, but within the UK, and is certain to help drive improved patient outcomes.

Are we making progress, and are we making it fast enough? Can we bridge the gap that elusively remains between our survival rates and those of our near neighbours? These are the fundamental questions we have considered in the latest study.

#### **This report**

- **Tracks progress made since the 2009 Pathfinder Study on key measures**
- **Defines actions and priorities**
- **Sets out opportunities for joint working across the NHS to achieve our common and important aim of saving lives**

We believe that progress is being made, but public health teams, GP commissioners, the NHS Commissioning Board, NHS trusts, and frontline medical staff all have a role to play in driving it forward, and the following pages will outline how this can be achieved. Joint working will be key to taking full advantage of the many opportunities that exist to improve both survival and quality of life for women with ovarian cancer. In particular the study’s Advisory Panel has highlighted :

- **There is proof that raising awareness of symptoms is effective, but the Government’s awareness pilots for ovarian cancer in England need to be extended quickly to regional and national levels to achieve a large impact. Action is also needed in Scotland, Wales and Northern Ireland.**

- **It is unacceptable for GPs to be refused access to diagnostic tests, and this should be challenged wherever it occurs. It is imperative that the new investment in direct access to diagnostic scans in England is utilised fully and is rolled out in the other home nations.**
- **The role of the Clinical Nurse Specialist (CNS) can help trusts improve not only patient experience but also cost effectiveness. However the current financial climate means CNSs are seriously compromised in their ability to support women across the patient pathway and lead on new initiatives improving efficiency, because they often have to undertake extra administration or general ward duties.**
- **There is a need to reverse the downward trend of participation in clinical trials. A larger number of clinical trials in ovarian cancer is required, together with efforts to overcome barriers for hospitals to participate, and greater empowerment for women so they know what might be available to them.**

Target Ovarian Cancer as an organisation has played an important role in driving progress since the first study, often partnering with other organisations. **Joint working between organisations will be the only way to deliver the rapid progress we so urgently need to improve outcomes for women.** In three years time we will undertake this major study once again. When we report back next time, we hope that we will be able to demonstrate substantial improvements in both survival and quality of life throughout the UK. Women with ovarian cancer, and their families, deserve nothing less.



**Professor Robert Haward**  
Chair, Target Ovarian Cancer Pathfinder Study Advisory Panel, Emeritus Professor of Cancer Studies (Leeds) and Associate Director of the National Cancer Research Network



**Annwen Jones**  
Chief Executive, Target Ovarian Cancer

# About the Pathfinder Study

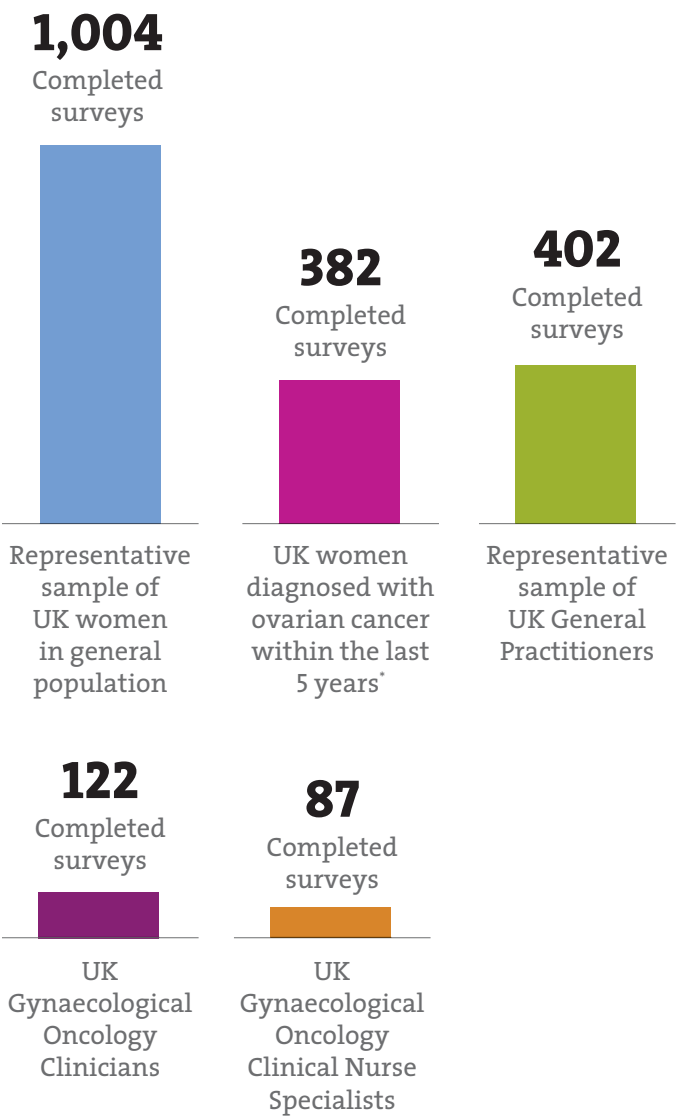
The Target Ovarian Cancer Pathfinder Study tracks the experience of those living with and working with ovarian cancer in the UK.

### 2009 Pathfinder Study highlights

In 2009 the results of the first Pathfinder Study shaped the work of Target Ovarian Cancer, focusing on the three main challenges: improving early diagnosis, finding new treatments, and supporting women with ovarian cancer. In addition it provided vital information to policy makers, politicians and professionals alike about the challenges and opportunities to improve survival and quality of life for women with ovarian cancer:

- **Demonstrating the need to improve levels of awareness amongst not only women in the general population, but also of the GPs diagnosing them. It showed many women (around a third) faced delays of six months or more between first seeing their GP and getting a correct diagnosis.**
- **Demonstrating for the first time, to the Department of Health, that the majority of GPs did not have direct urgent access to diagnostic scans. This has led to a multi-million pound investment to improve access, as part of Improving Outcomes – A Cancer Strategy (2011).**
- **Showing the most effective ways for GPs to update their knowledge. This led to our award winning, free to access learning tools developed with BMJ Learning that have proved extremely popular.**
- **Showing that an in-depth high-resolution study into the differences in international survival would be feasible, to tease out the many and complex reasons for the UK’s poor survival rates. The results of a feasibility study fed in to the Department of Health’s International Cancer Benchmarking Partnership Study (ICBP).**

### 2012 Pathfinder Study component parts:



Full notes on methodology and interview dates available in the full report.

\* The 2009 survey for women with ovarian cancer did not have a cap on time since diagnosis and the 2012 survey excluded women who had taken part in the previous study.



### Role of 2012 Advisory Panel and research agency

The Advisory Panel reviewed the proposed structure of the study, and helped to develop the component parts, working with both Target Ovarian Cancer and our research partner Ipsos MORI (Synovate in 2009). All fieldwork was undertaken between February and May 2012. Analysis of the data has been undertaken by Ipsos MORI and carried out in accordance with the requirements of the international quality standard for market research ISO 20252:2006.

The charts and tables in this report do not include any base sizes and notes. This information can be found in the full report.

The full results of the 2012 study, including the methodology (report by Ipsos MORI), are available to download from our website:

**[www.targetovariancancer.org.uk/pathfinder](http://www.targetovariancancer.org.uk/pathfinder)**

Alternatively you can order a hard copy by calling **020 7923 5470**

or emailing **[pathfinder@targetovarian.org.uk](mailto:pathfinder@targetovarian.org.uk)**

The images used in this publication feature people who have been involved in Target Ovarian Cancer's work and publications. Permission must be sought before reproducing any of them.

### Project team

Frances Reid, Director of Public Affairs and Communications, Target Ovarian Cancer  
Dr Sharon Tate, Public Affairs Manager, Target Ovarian Cancer

### The 2012 Advisory Panel

#### **Chairman: Professor Robert Haward\***

Emeritus Professor of Cancer Studies (Leeds) and Associate Director of the National Cancer Research Network

#### **Joanna Barker\***

Chairman of the Board of Trustees, Target Ovarian Cancer

#### **Mr Laurence Brown**

President of the British Association of Gynaecological Pathologists, University of Leicester

#### **Dr Tracie Miles**

President, National Forum of Gynaecological Oncology Nurses, Royal United Hospital, Bath

#### **Dr Alison Farmer**

Visiting Lecturer in Psycho-Social Oncology, University of Southampton

#### **Professor Willie Hamilton\***

Professor of Primary Care Diagnostics, Peninsula College of Medicine and Dentistry, University of Exeter

#### **Dr Kim Hawker**

Patient advocate

#### **Annwen Jones\***

Chief Executive, Target Ovarian Cancer

#### **Dr Sean Kehoe**

President of the British Gynaecological Cancer Society, University of Oxford

#### **Professor Henry Kitchener**

Ex officio, Chair of Target Ovarian Cancer Scientific Advisory Board, University of Manchester

#### **Professor Jonathan Ledermann\***

Chairman, National Cancer Research Institute Gynaecology Clinical Studies Group, University College London

#### **Gillian Luis-Ravelo**

Patient advocate

#### **Robert Luxton**

Relative advocate

#### **Professor Iain McNeish\***

Chairman, National Cancer Research Institute, Ovarian Sub-Group, University of Glasgow

#### **Mr Andy Nordin\***

Clinical Advisor to the National Cancer Action Team & NHS Improvement, Chair of the National Group of Gynae Cancer Network Leads and Chair of the National Cancer Intelligence Network Gynaecology Site Specific Clinical Reference Group

#### **Lindy Waldron\***

Patient advocate

#### **Howard Webber\***

Relative advocate

\* Indicates membership of the 2009 Advisory Panel

# 1. The journey begins – awareness

**Women need to know that the symptoms they are experiencing might be serious, otherwise they risk not seeking appropriate help. After pancreatic cancer, ovarian cancer has the lowest proportion of diagnoses where the cancer is confined to the organ.**

In the 2012 study, women diagnosed with ovarian cancer in the last five years were asked about their knowledge of ovarian cancer, prior to their diagnosis. Just 3% felt they knew a lot about the disease, and 55% said they had heard of the disease but did not know anything about it. Whilst four in ten women visited their GP within one month of experiencing symptoms, half of the sample took considerably longer.

In recent years ovarian cancer charities have sought publicity for the symptoms of the disease through the media, with a focus around Ovarian Cancer Awareness Month each March. In April 2011, the National Institute of Health and Clinical Excellence (NICE) produced the first ever guidance on 'The recognition and initial management of ovarian cancer'.<sup>1</sup> This updated the evidence base on key symptoms, and emphasised the importance that frequency and persistency play in distinguishing between ovarian cancer and more common but less serious conditions.

Ovarian cancer symptoms usually occur more than 12 times a month. They include:

- **Persistent bloating/abdominal distension**
- **Pelvic/abdominal pain**
- **Difficulty eating/feeling full**
- **Urinary frequency/urgency**

As part of the study, women in the general population were once again asked about their knowledge of ovarian cancer symptoms. The results showed that whilst general awareness of the disease remains fairly high and consistent with 2009, knowledge of ovarian cancer signs and symptoms is increasing, albeit at a relatively slow pace, and from a low base. Women however still lack the confidence to identify a symptom of ovarian cancer.

**Time to see GP after first experiencing symptoms:**

**1 in 10** not seeing GP



**4 in 10** going within 1 month



**2.5 in 10** between 1 and 3 months



**1 in 10** between 3 and 6 months

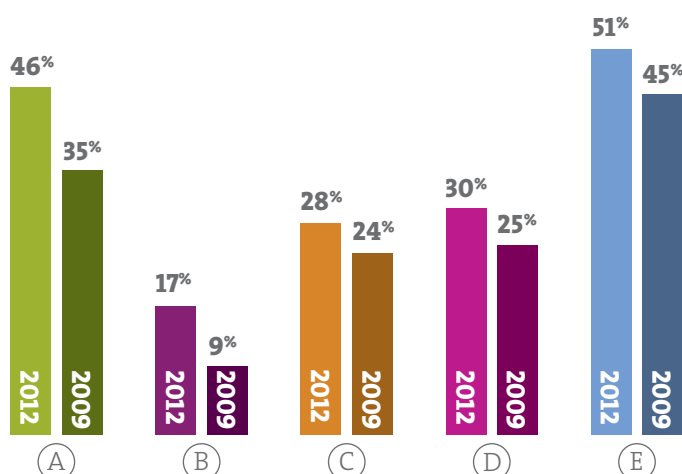


**1.5 in 10** taking 6 months or more



\* proportions rounded

**The chart shows significant increases in symptom awareness between the 2009 and 2012 study:**



- (A) Spontaneous mention of one or more symptoms
- (B) Spontaneous awareness of the most commonly experienced symptom – persistent bloating
- (C) Spontaneous awareness of pain in the abdomen
- (D) Prompted awareness of difficulty eating
- (E) Prompted awareness of feeling full





It was a matter of concern that confidence in spotting a symptom of ovarian cancer remains very low, with just 3% of the population saying they felt very confident.

Urinary frequency/urgency did not see significant improvements in awareness. These symptoms were only identified as key symptoms in April 2011 when the National Institute of Health and Clinical Excellence issued guidance on ovarian cancer.

It should be noted from the 2012 data that a significantly higher proportion of women in the general population educated to degree level or higher were spontaneously able to mention a key symptom (59%) than those with no qualifications (33%). This emphasises the importance of campaigns reaching across social spectra. Women largely remain unaware that the risk of ovarian cancer increases with age (2012-60%, 2009-65%). And nearly half of all women incorrectly think cervical cancer screening will detect ovarian cancer (47%).

Discouragingly 2012 data revealed a significant decrease in the proportion of women in the general population who say they would visit their doctor within one week of experiencing a symptom. They gave various reasons for this including 'worry about wasting a doctor's time', 'being too busy', 'difficulty making an appointment' and 'too many other things to think about'.

In 2009 the panel called for a national awareness campaign on the symptoms of ovarian cancer. In January 2013, England will pilot the first local awareness campaigns for ovarian cancer as part of its Be Clear on Cancer programme.

### 2012 Advisory Panel comments

In reviewing the latest evidence, the panel felt strongly that charity awareness-raising activities had impacted positively on awareness, but in order to raise levels of awareness sufficiently, the Government led pilots must be extended into a national campaign. Results from the first national bowel cancer campaign show improved unprompted knowledge of the most common symptom, blood in poo, from 27% to 42% in just 3 months. The panel was concerned at the lack of specific plans in Scotland, Wales and Northern Ireland to address this issue.

### KEY ACTIONS FOR PUBLIC HEALTH TEAMS

- **National campaigns are needed reaching across social groupings. The risk with age, and confusion with cervical cancer should be addressed**

### WHAT'S AVAILABLE

- **The Ovarian CAM (Cancer Awareness Measure)<sup>1</sup>**
- **Target Ovarian Cancer trains women to raise awareness in their local community through its 'Let's Talk' programme, and has supported the Be Clear on Cancer local pilots with bespoke training for health advocates**
- **Target Ovarian Cancer leaflets, posters and awareness guides**

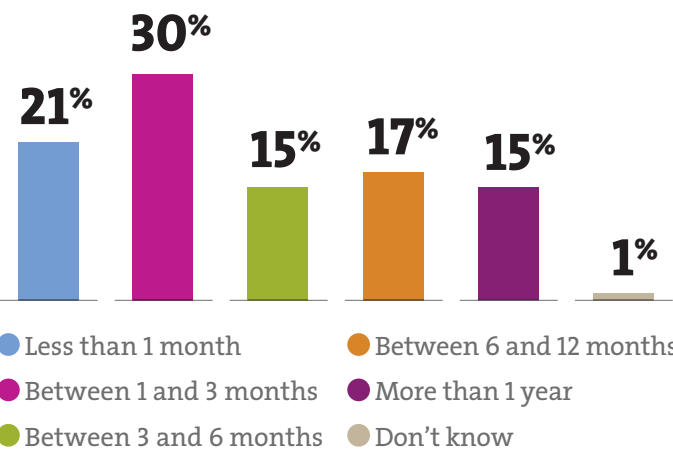
For more information on Target Ovarian Cancer awareness resources, visit

**[www.targetovariancancer.org.uk/letstalk](http://www.targetovariancancer.org.uk/letstalk)**

## 2. Choosing the right road – challenges and opportunities in primary care

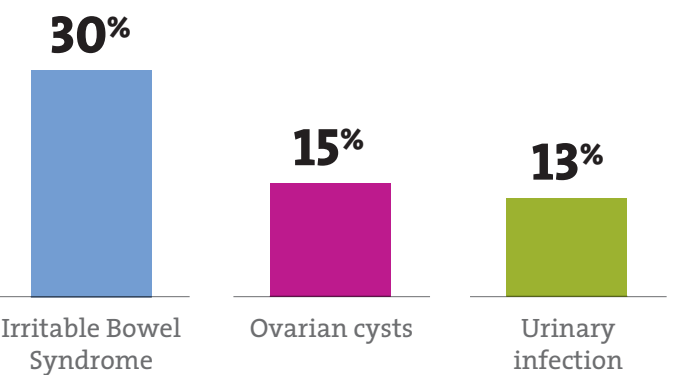


Time taken for women to get a correct diagnosis after first visiting GP:



Due to rounding, percentages do not add up to 100%.

The most common reason given to women by their GP for the cause of their symptoms was:



When a woman visits her GP with symptoms that could indicate ovarian cancer, the GP needs to recognise the possibility and access diagnostic tests as swiftly as possible. Otherwise delays in diagnosis will occur, potentially impacting on a woman’s chance of survival, and we will not reduce our shocking rates of diagnosis in A&E (32%).

### The women’s perspective

89% of the women with ovarian cancer surveyed visited their GP about their symptoms. For one in five women with symptoms the diagnostic process was quick and took place within one month of first visiting their GP. For the remaining majority of women the process was slower, and for almost a third of women, their diagnosis came more than six months after that first visit.

Whilst seven in every ten women were concerned about their symptoms, only 34% felt their GP took their concerns very seriously, and one in five said their concerns were not taken seriously at all. Looking at those women diagnosed with early stage ovarian cancer (stage 1 or 2), half felt their concerns were taken very seriously, but amongst those diagnosed with late stage disease (stage 3 or 4) it fell to just one in four.

*“My GP was very good and acted speedily, at the time I didn’t want to go in hospital but I am very glad now that he sent me in.”*

*“Upset about misdiagnosis, and the long wait for treatment to begin.”*



***“I feel that the care I received was of a low standard and that my symptoms and feelings were not taken seriously.”***

Just one-third of women (32%) were aware that they could be diagnosed with ovarian cancer when they went for tests that led to their diagnosis. Of this group, a third had been told by the referring doctor, four in ten read information independently that suggested they might have ovarian cancer, and three in ten were told by those conducting the tests. Unsurprisingly, two-thirds of women were shocked when they received their diagnosis. In 2009, significantly more women said they knew they could be diagnosed with ovarian cancer (51%).

#### **GP perspective**

In the period of time since the last study in 2009, a range of guidance and learning tools has been published (see page 13). The evidence from the 2012 study shows the beginnings of changes in knowledge, attitudes and referral patterns and the panel were very encouraged by the progress being made. However they acknowledged that much more needs to be done to update GPs and ensure they have the access they need to diagnostic tests, so that delays in diagnosis can be reduced.

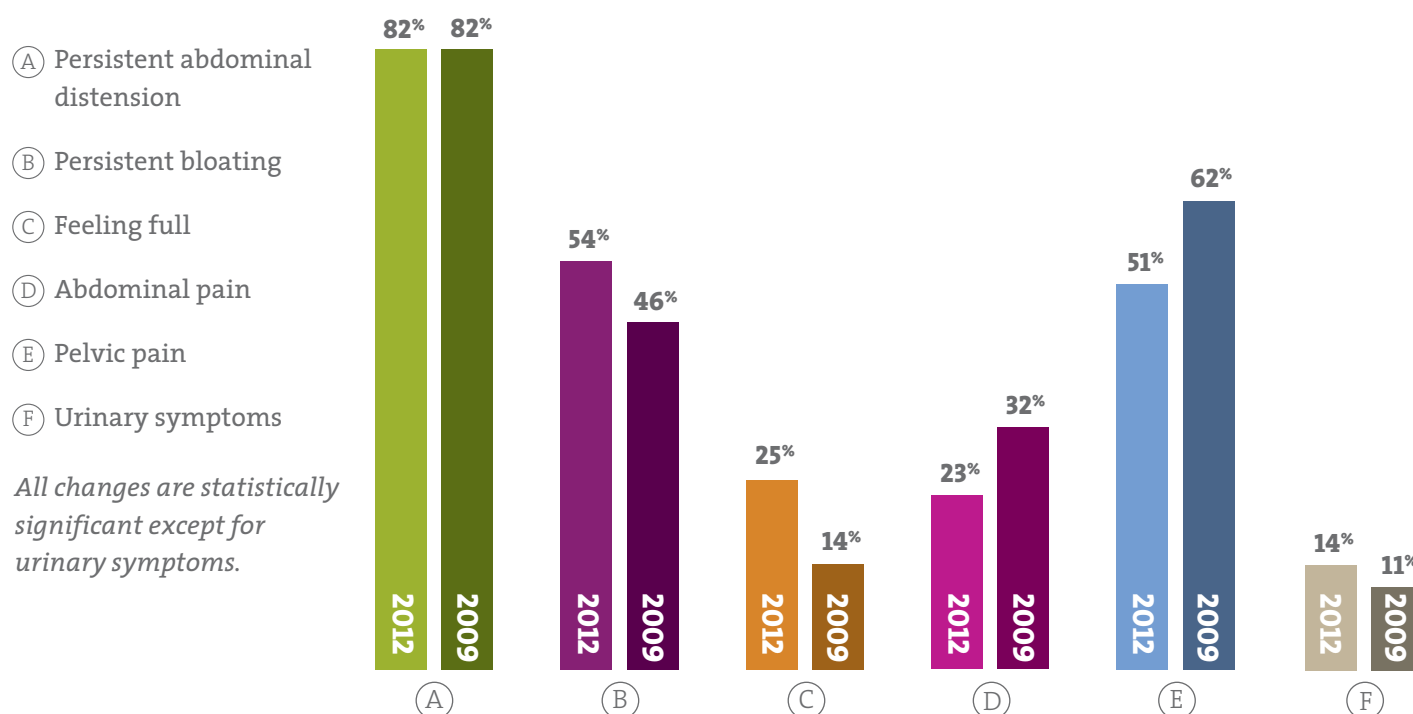
***“I was lucky at the time I went to see my GP there had been an ovarian cancer awareness campaign in my surgery and there were posters all over the wall. I went to my GP thinking it was IBS and was shocked to think it could be ovarian cancer. The GP I saw was very sensitive and sympathetic.”***

Specifically the following was noted:

**Attitudes:** Encouragingly, compared to 2009 there is a significant decrease (albeit modest) in the proportion of GPs who feel ovarian cancer is a silent killer (91% vs. 96%), and a decrease in those believing symptoms present themselves only in late stage disease (67% vs. 79%). When asked whether women with ovarian cancer are more likely than those with IBS or other benign conditions to experience very frequent, sudden onset and persistent symptoms, 42% think this is true (compared to 31% in 2009).



**Symptoms:** The following chart shows the changes in proportion of GPs concerned about key symptoms between 2012 and 2009



**Risk factors:** The survey shows that GPs' knowledge of risk factors for ovarian cancer show some improvement, with an increase in those recognising that a family history of breast cancer can increase the risk of developing ovarian cancer (89% up from 83%). However, most GPs are not aware that women are at increased risk of ovarian cancer if they have a strong family history of ovarian cancer on their father's side of the family. Only 10% knew this, 40% said there was no risk association, and 50% said they did not know.

**Referrals:** The survey shows that in the last year, GPs have increased the number of referrals for suspected ovarian cancer from an average of two to three. However 17% of GPs had not made any referrals, and 30% only made one.

**Tests and results:** Compared to 2009 there has been a significant reduction in the proportion of GPs undertaking abdominal (8% points decrease) or vaginal examinations (13% points decrease), but an increase in the use of CA125 blood tests (13% points increase).

Around one in three GPs feel that access to diagnostic tests has improved in the last year, and they are significantly more likely to be from NHS Trusts implementing the NICE guidance. There has been a small increase in the number of GPs who have direct access to urgent transvaginal ultrasound from 47% to 52%. In

England, the implementation of direct access to this test for all GPs will play an extremely important part in speeding up diagnosis. However the panel was very concerned to hear that one in ten GPs had been refused tests (either CA125, TVU or abdominal scans) in the last year.

There have been significant improvements in the speed of tests and results, with improvements for both abdominal and transvaginal ultrasound. However for one in four of these tests, it still takes more than a month but less than two months for the test to be carried out and results received.

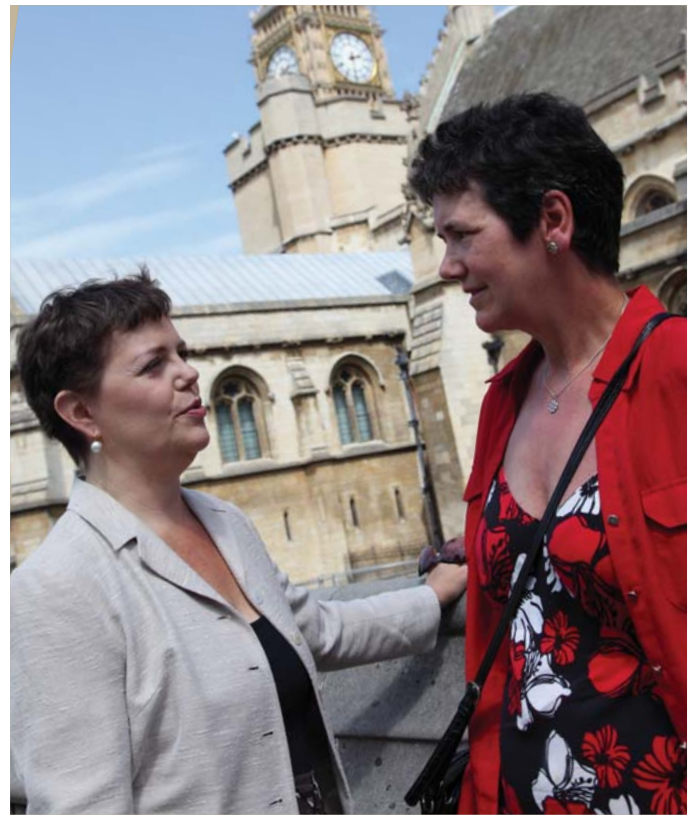
**Initiatives that would support clinical practice diagnosing ovarian cancer:** 70% of GPs in England, Wales and Northern Ireland were aware of the new NICE guidance, considerably more than the 24% of GPs in 2009 who were aware of the Department of Health's Key Messages on Ovarian Cancer. The implementation of the NICE guidance was perceived as being the most able to support GPs' clinical practice in diagnosing ovarian cancer more effectively (50%). This was closely followed by improved access to diagnostic tests (48%) and closer relationships with secondary care colleagues (43%). When clinicians in secondary care were asked, 70% agreed that providing primary care with a named secondary care contact could improve the speed of the referral. They also felt (77%) that the speed of internal





referrals within secondary care could improve the speed of diagnosis for women with ovarian cancer i.e. without necessarily referring back out to the GP.

**Learning tools:** Some 18% of the GPs surveyed had completed Target Ovarian Cancer's BMJ Learning CPD Tool on ovarian cancer, launched in 2010 and updated to reflect NICE guidance in 2011.



### 2012 Advisory Panel comments

The panel were very encouraged by the clear shifts in GP knowledge and attitudes, and by the impact that has been made by the online learning tools. However it is important to ensure that uptake of these tools is increased, and that above all, GPs are allowed full access to the tests they need to make as early a diagnosis as possible.

### KEY ACTIONS FOR CLINICAL COMMISSIONING GROUPS AND GPs

- Ensure all GPs in all UK nations have direct access to urgent TVU
- Ensure GPs are not having requests for tests refused
- Ensure GPs update their knowledge using accredited learning tools
- Ensure NICE guidance is implemented in England, Wales and Northern Ireland, and that Scotland publishes its new SIGN guidance as soon as possible
- Establish links between primary care and secondary care clinicians to help speed up appropriate referrals for those who need it most

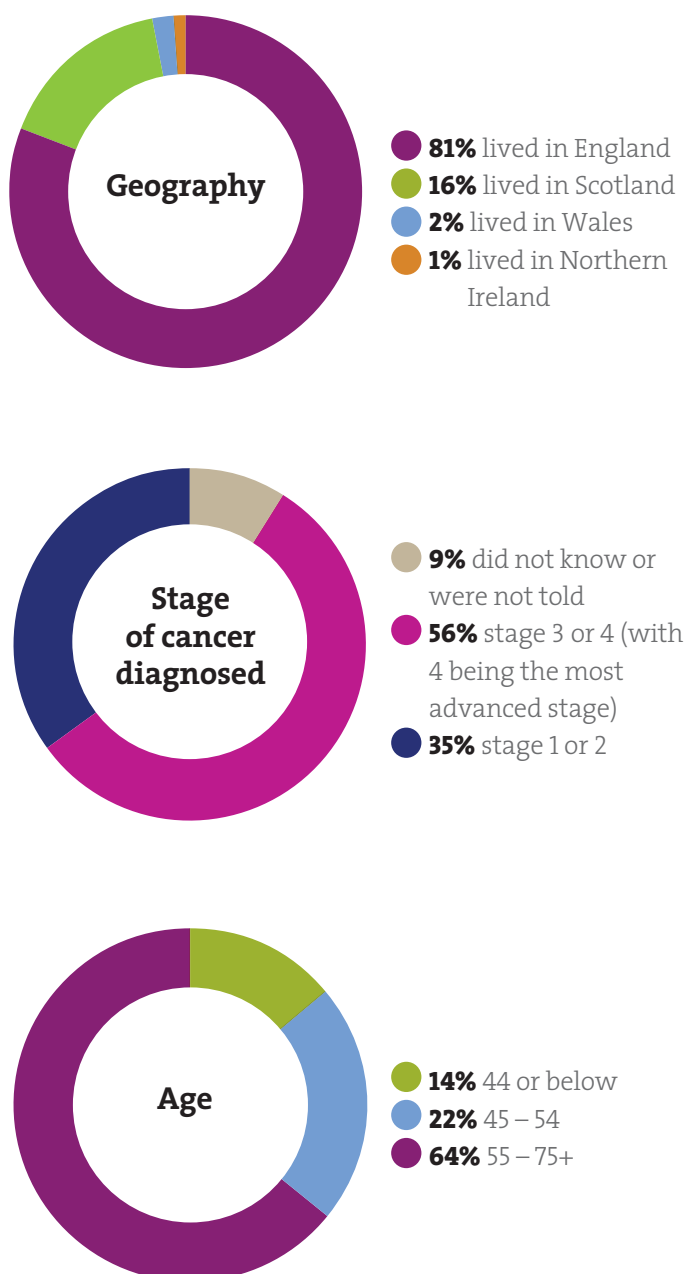
### WHAT'S AVAILABLE

- NICE guidance CG122 (2011), NICE Quality Standard QS18 (2012), DH Access to Diagnostics guidance (2012)
- Free to access NICE compliant online CPD training for GPs: Target Ovarian Cancer with BMJ Learning (2011 and 2012)
- Target Ovarian Cancer pathway guidance flagpen (2012)
- Target Ovarian Cancer factsheets for those being sent for CA125 and ultrasound tests (2012)

For more information and links visit  
[www.targetovariancancer.org.uk/gp](http://www.targetovariancancer.org.uk/gp)

# 3. On the road – diagnosis and treatment

The 382 women taking part were diagnosed with ovarian cancer within the last five years, and had not taken part in the previous study:



## Patient perspectives

In general many of the findings of the 2012 study were similar to those highlighted in 2009. They represent a great range of experiences from very positive to very negative. Where the surveys overlap there are similarities to the ovarian cancer data from the National Cancer Patient Experience Survey 2012.<sup>1</sup>

## At the point of diagnosis

90% of women surveyed were given their diagnosis face to face with a health professional. However, for one in ten, the news was delivered via a telephone call. A third of women were not offered the choice to have a family member present at the point of diagnosis. Six in ten women were given enough information by the doctor or nurse to answer any questions they had at the point of diagnosis; but a quarter (26%) felt they did not get all the information they needed.

## Treatment

The vast majority of women surveyed underwent surgery (90%) including 11% who had undergone surgery for a recurrence of their cancer. 91% of women had been treated with chemotherapy with 40% of women receiving chemotherapy prior to their surgery. In total 46% of the women had either experienced a recurrence of their cancer, or their cancer had never gone away in the first place.

In general women view the phase of active treatment very positively, though there is always room to improve their experience. In particular this could be achieved with information relating to surgery and chemotherapy. The panel was very pleased to note that there had been a considerable uplift in data relating to information at the time of surgery. However for a significant proportion of women there were still gaps in this information. Only 60% received clear written information, and 74% said health professionals gave them enough time to ask questions. In relation to chemotherapy 76% received written information, but only 44% felt they had been given all the information they needed to make a decision.

**Choice of chemotherapy and side effects**

The survey shows that since 2009, there had been a sharp drop in the number of women being offered a choice of chemotherapy (24% vs. 57%); however the panel felt this probably reflected new data from studies, which favour certain treatments over others. Women were asked what factors they would consider when choosing chemotherapy. By far the most popular response was prolonging life (73%), compared to side effects (26%).

These figures should not underplay the impact that side effects can have on women with ovarian cancer. Women were asked what were the most difficult side effects to deal with, and how commonly they had experienced them.

**Side effects and their impact:**

- Proportion of women for whom this symptom caused most concern**
- Overall proportion of women experiencing this symptom**

**Tiredness**



**Feeling or being sick**



**Constipation**



**Hair thinning or hair loss**



**Tingling or numbness in hands/feet**



Other symptoms experienced commonly were aches/pains (53%), sleep loss (53%) and muscle pain (49%).

**Access to Clinical Nurse Specialists (CNS)**

In 2009, the CNS was cited as the single most important source of support for women with ovarian cancer. Encouragingly in 2012 there was a significant increase in the number of women being given the contact details of a CNS (75% vs. 55% in 2009) at the point of diagnosis. Overall access to CNSs is high (89%); however one in ten women do not have access to this vital resource, and for 17% of women, there is no continuity in the CNS they see. A matter of concern for the panel was the large drop in the proportion of women citing the CNS as their most important source of emotional and practical support. They were concerned given the responses from CNSs and clinicians that this indicated whilst quantity (in terms of access to a CNS) had improved, there had been a considerable drop in the quality of help that CNSs were able to give.

**2012 Advisory Panel comments**

Comments regarding the role of the CNS are dealt with in detail on page 27. The panel believe that trusts should seek to optimise patient experience wherever possible, including the provision of information.

**KEY ACTIONS FOR TRUSTS AND CLINICAL TEAMS**

- Address information gaps at diagnosis, chemotherapy and surgery
- Ensure women get help to cope with the effects of treatments

**WHAT'S AVAILABLE**

- Information prescriptions (England)
- Target Ovarian Cancer pathway guides (all Information Standard accredited) contact [info@targetovarian.org.uk](mailto:info@targetovarian.org.uk) and see page 30 for more details



## 4. Clinical trials – perspectives of patients and clinicians



**The NHS Constitution handbook (2012) states “The NHS will do all it can to ensure that patients, from every part of England, are made aware of research that is of particular relevance to them.”<sup>1</sup>**

### **Patients**

On the whole, most women are open to the idea of clinical trials. Just 10% categorically said they would not want to participate in clinical trials. It is altruistic rather than personal reasons that dominate women’s wish to participate. Overall 74% of women interested in trials said that it was important to participate so that knowledge and treatment can advance, 67% said it was important to give other women a good chance of surviving in the future. This compared to 61% of women who wanted to take part in trials to give themselves the chance of extending their life as long as possible, and 54% who felt reassured by the extra tests and hospital check-ups that taking part in a trial might provide.

The panel were concerned to learn that just 30% of women (down from 39% in 2009) had been asked if they would like to enter a clinical trial. Women diagnosed two or more years ago were more likely to have been asked than those with a more recent diagnosis. Consistent with results in 2009, some 24% of women initiated discussions about clinical trials themselves. The panel were also interested to learn of the high proportion of women who would or might be prepared to travel to other hospitals so that they could take part in a trial (69%). Just 10% would not be prepared to travel beyond their treatment centre.

66% of women who were asked, or who volunteered, ended up taking part in a clinical trial. For those who decided against a trial, the most common reason given was that the increased visits to the centre would put too much of a strain on them/family.





## Clinicians

The majority of clinicians surveyed (83%) say their centre or unit is involved in clinical trials. Seven in ten clinicians say they would like their centre or unit to participate in more clinical trials, and a similar proportion say barriers exist to such a move. Increased bureaucracy associated with more clinical trials is the most common barrier (45%), followed by a lack of time to recruit patients (38%) and a lack of suitable trials (35%). When asked what resources would be required to enable their hospital or centre to participate in more clinical trials the overwhelming response was for more administrative support, more nurses and more time:

***“More time allowed for clinic appointments to discuss trials and recruit patients.”***

***“It’s not just about resources – it’s about having subtype specific trials e.g. for clear cell, low grade serous cancers. However more research nurses and trial administrators would undoubtedly help.”***

Just over a quarter of all clinicians (27%) agree that it is not easy to keep up to date with available clinical trials. Clinicians use a variety of sources to keep their knowledge up to date, with the British Gynaecological Cancer Society annual meetings being cited most commonly (34%). Other sources include the National Cancer Research Network (NCRN) and National Cancer Research Institute (NCRI) websites (15% and 11% respectively). A lesser proportion uses a variety of means including multi-disciplinary team (MDT) meetings.

## 2012 Advisory Panel comments

The panel stressed the importance of having accessible trials open to women around the UK, and that more must be done to harness women’s willingness to participate. Whilst there is clearly a need for clinicians to think more widely than just their local centre, they urged charities such as Target Ovarian Cancer to find better ways to make information available to women interested in trials, so that women can be proactive.

A significant proportion of clinicians admit to finding it hard to keep up to date with which trials are currently available. The panel were aware that a lack of publicly available information about clinical teams meant it was hard for charities such as Target Ovarian Cancer to disseminate information about clinical trials widely. The panel recognised that the barriers to increasing the numbers of clinical trials were not exclusive to ovarian cancer and therefore encouraged Target Ovarian Cancer to link up with those already working in this area to strengthen calls to action.

## KEY ACTIONS FOR TRUSTS AND CLINICIANS

- **Make sure clinicians and patients know that patients have a right to be made aware of research relevant to them**
- **Make sure clinicians are aware of what trials are available not only in their own hospital, but also at neighbouring centres, and ensure women are given the chance to discuss trials**
- **Work to reduce the barriers to hospitals participating in more clinical trials in ovarian cancer**
- **Share clinical contacts with Target Ovarian Cancer to allow better dissemination of information**

## WHAT’S AVAILABLE

- **The Target Ovarian Cancer Clinical Trials Information Centre [www.targetovariancancer.org.uk/clinicaltrials](http://www.targetovariancancer.org.uk/clinicaltrials)**
- **Information Standard approved guides from Target Ovarian Cancer which encourage women to talk about trials (see page 30)**
- **Target Ovarian Cancer’s national research programme ([www.targetovariancancer.org.uk/research](http://www.targetovariancancer.org.uk/research))**

# 5. Living with ovarian cancer – emotional, practical and financial support needs

The aim of the National Cancer Survivorship Initiative in England is to ensure that those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible. In Scotland there is a focus on self-management of long-term conditions to improve health and wellbeing. No matter where they live in the UK, Target Ovarian Cancer seeks to ensure that women with ovarian cancer have a long and good life. It has developed resources and regional events to help women, and those caring for them to help achieve this.



### Emotional support

In total two-thirds of women surveyed have needed emotional support (64%) at some point since their diagnosis. 90% of them have needed it at different points of the pathway, with women diagnosed with late stage disease most in need of support. For the whole group of women surveyed, one-third were offered help, one-third asked for help and a quarter neither asked nor received help when they needed it.

Most Clinical Nurse Specialists (55%) offer support at one key point (most commonly on diagnosis) with just 30% able to offer support along the whole patient pathway. However as can be seen from the table below, there are very significant needs at other times for women, depending on the cancer’s stage at diagnosis.

Support needs for women with ovarian cancer	All women	Stages 1 & 2	Stages 3 & 4
At point of diagnosis	47%	38%*	<b>52%</b>
After initial treatment	49%	<b>54%</b>	45%*
If the cancer returned	41%	28%*	<b>50%</b>
If told it’s incurable	31%	16%*	<b>37%</b>
No particular time	10%	15%	8%

Figures in bold are significantly higher than those marked with an asterisk.

The ability of CNSs to support women with ovarian cancer is discussed more fully on page 22.

Women require emotional support for a number of specific issues. Coping with the fear of recurrence (65%) scores most highly, followed by getting their lives back on track after treatment (55%). Women have also needed support with feelings of isolation (38%), issues relating to family and friends (33%), body image (28%), regaining sexual intimacy with a partner (17%) and the menopause (16%).

***“I have not told most people other than family and a few friends. It is too emotionally difficult for me to talk about it. However it is unpleasant not being open with people although I am told that I am cured.”***

***“If my family had not been so supportive (my husband was brilliant), I think I would have gone under. No support was forthcoming from any department. Information was not even offered.”***

***“Dealing with diagnosis. Feelings of helplessness, when trying to get information from the professionals (consultants).”***

Findings from the 2012 study show that women use multiple sources for emotional support. In 2012, friends (67%) and family (66%) have been key sources. Around a half of women were given support by a CNS (52%). Women with ovarian cancer are also an important source of support for each other (34%) whilst other sources of support used by women include counsellors (32%), charities (30%), support groups (27%), GPs (27%) and consultants (18%).

***“Fear of what might happen and fear of death.”***

***“Feelings of worth or meaning in life post treatment.”***

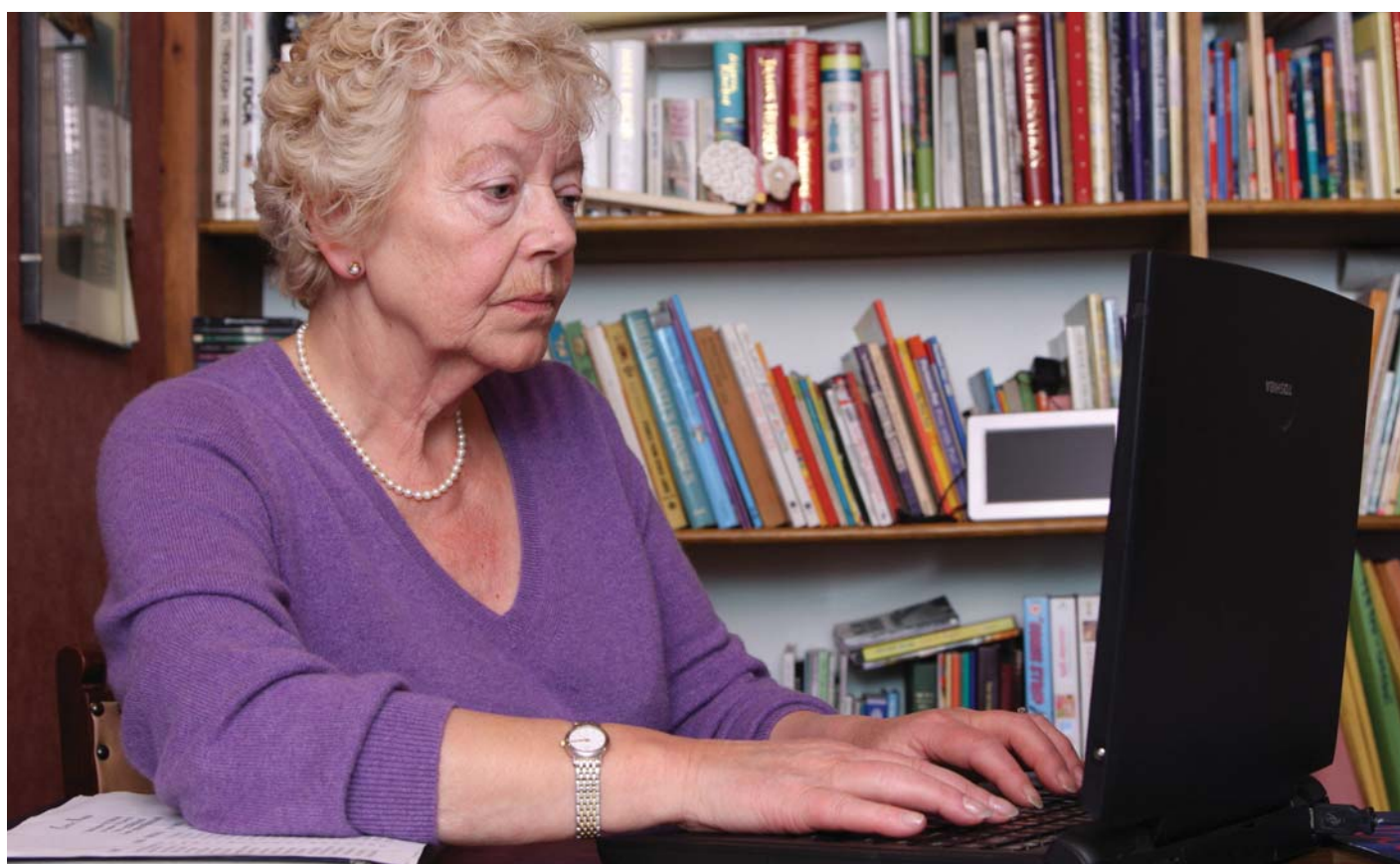


***“The support of others with the disease who know where I am coming from has been most helpful. I am a strong person and a control freak and loss of control over my life has been most difficult to handle.”***

***“I didn’t think I would need support as I have a very supportive partner and friends. However I would like to talk to someone else who is not a part of my close circle of friends, family, just to ‘get things off my chest’.”***

In 2009, CNSs had provided similar levels of support to women. However when asked who had been the single most important source of support, the results this time showed that the CNS dropped some 19% points, from the single most important source to just 7%, eighth place behind family, friends, charities and others.





### Practical support

Turning to practical support, some seven in ten women have had needs in this area, with help with daily tasks being most commonly reported (44%) followed by transport needs (35%). Of those with practical support

needs, women rely most heavily on friends and family (77%), but there has been an increase in help offered by Macmillan nurses (40% vs. 25% in 2009) and CNSs (32% vs. 21%).

Practical support needs	Types of support needed	Types of support received	Most important
Help with daily tasks	44%	13%	4%
Help with transport	35%	44%	12%
Benefits advice	33%	18%	6%
Advice on diet and nutrition	32%	23%	9%
Advice on exercise and lifestyle	27%	7%	5%
Other financial support	17%	34%	9%
Home adaptations	7%	46%	18%
Support not required	31%	-	-



## Financial support needs

The 2012 survey asked for the first time about financial needs which impact not only on the women directly, but their family members.

Over half of women with ovarian cancer surveyed have experienced financial hardship as a result of their diagnosis, and of these, six in ten have needed to claim disability and incapacity benefits. Furthermore, 53% had seen a rise in their daily bills, 52% had to give up work, and four in ten women found it difficult to enter into correspondence and fill out financial forms when they were unwell. 22% had partners or close family members who had reduced their working hours in order to help with their care.

## Ability of professionals to refer to others

In terms of dealing with women's needs, CNSs have varied access to support services led by allied health professionals. In particular the following proportions of CNSs do not have access to:

- Occupational therapy 38%
- Dieticians 40%
- Clinical psychotherapy 46%
- Complementary therapy 46%

***“Yes, you must push to see someone.... I have mentioned it to my nurse consultant and GP and they said they would send me to see someone but two years later and asking a lot, I am still waiting.”***

## 2012 Advisory Panel comments

The panel noted the range of practical, emotional and financial needs of women, and that their needs were distributed along the patient pathway. They were concerned that whilst CNSs are more widely available to women, their capacity to deliver the depth of support is waning. They were concerned that 55% of CNSs were only able to offer support at one point along the patient pathway. This, the panel believes, is due to the increasing strains on the role, which are discussed in the next section.



## KEY ACTIONS FOR TRUSTS AND CLINICIANS

- Ensure information is available for women at all points along the patient pathway, with a focus on psychosocial aspects of living with cancer
- Ensure there are appropriate referral pathways in place to deal with women's needs

## WHAT'S AVAILABLE

- Target Ovarian Cancer pathway guides – see page 30 for information
- [www.targetovariancancer.org.uk/ihaveovariancancer](http://www.targetovariancancer.org.uk/ihaveovariancancer), including a regularly updated 'Ask the Experts' section
- Target Ovarian Cancer's online and searchable directory to locate nearest support groups
- Target Ovarian Cancer Being Together days, which take place around the UK run in conjunction with local CNSs

## 6. Professional perspectives



### Clinical Nurse Specialists and clinicians\* were asked about a number of issues identified by the Advisory Panel.

These included but were not limited to:

- The impact of the recent economic climate on the ability to provide services for women with ovarian cancer
- The role of the Clinical Nurse Specialist
- The role of the multi-disciplinary team
- Developments in drug/surgical treatment and the sector's ability to plan for these developments
- Value of Target Ovarian Cancer services
- Future priorities for Target Ovarian Cancer

In addition to the issues surrounding clinical trials, which have already been discussed, the survey participants felt most strongly about the role of the Clinical Nurse Specialist.

**Clinical Nurse Specialists:** Post holders are key to improving patient experience and efficiency within the departments in which they work. Yet they are getting less and less time with patients, less time working on nurse led initiatives, and spending more of their time on work which could be carried out by others who are less qualified, such as administration, or on other

general ward duties. Both clinicians and CNSs are seeing the frontline impact of budget restraints and cuts on the care they can provide for women with ovarian cancer.

Three-quarters of CNSs surveyed feel that the recent budget constraints have had a detrimental impact on the level of service they can provide:

- 52% are spending less time on nurse-led initiatives such as follow up clinics, symptoms management
- 45% are spending more time on administration
- 41% have less consultation time with women
- 34% are less able to support patient groups

In total 87% of CNSs say they perform duties that could be carried out by an administrator, and for those nurses who provided a full breakdown of their weekly tasks, they appeared to spend some 16% of their time on these tasks. Additionally 49% were often asked to take on non-specialist duties.

***“Due to the financial demands of the trust I work in, this post was reduced from full time to 32 hours per week. The clinical admin side of the job is increasing: this is so the trust can improve their documentation to increase their levels of CNST (Clinical Negligence Scheme for Trusts). The volume of patients is gradually increasing and it is a continuing battle. The admin ends up being done out of hours.”***

\*Including Surgical Gynaecological Oncologists, General Gynaecologists working in ovarian cancer, Medical and Clinical Oncologists, Gynaecological Pathologists, General Histopathologists, and Radiologists

Well over half of all CNSs would like to provide a range of nurse-led follow up clinics/initiatives as follows:

Provision of nurse led clinics/initiatives	Currently provide	Would like to provide
Follow up clinics for women who have finished first line treatment	31%	56%
Improving symptom management	23%	62%
Follow up clinics for women with recurrent ovarian cancer	19%	56%
Supporting and encouraging self-management	16%	70%

Lack of time is the biggest barrier to implementation due to workload (65%) followed by lack of funds from Trust/PCT or lack of support from Trust/PCT (32% and 27% respectively).

Just four in ten CNSs have been involved in submitting a business case in the last two years; a quarter were to increase the number of full or part-time posts, 10% to increase the current hours of an existing CNS post, and 7% for other reasons. This is despite some 57% of CNSs believing there are insufficient numbers of CNSs in their unit or centre. Most cases are submitted in the specialist centre setting, and from CNSs who are not acting as sole operators.

Keeping up to date with developments in ovarian cancer can prove challenging for many CNSs. Just 22% say they have time to stay up to date on the latest treatments. 65% of CNSs say they are able to take study leave if they need to attend training, but as the following quote shows there are concerns over what is allowed:

***“We cannot go to study days run on ovarian cancer as these are not classed as essential training...This can leave you frustrated.”***

The clinicians show very strong support for the role of the CNS. Overwhelmingly (96%) agree that the role of CNS is critical in providing supportive care for women. Around three quarters of clinicians believe the CNSs are central to improving effectiveness of local services (71%) and improving the level of support for women with ovarian cancer (76%).



However a majority of clinicians say CNSs are not able to spend sufficient time with patients due to workload or pressure to perform other duties (62%), and almost a half say CNSs' time with patients has decreased in the last three years (46%).





### **Impact of current financial climate**

A large proportion of clinicians have experienced some cuts (59%) or frozen budgets (21%) in the last three years. One in five clinicians say this has not impacted on the care of women with ovarian cancer. However a third (36%) say it has had an adverse impact on the quality of service provided to women with ovarian cancer:

***“One of the most striking areas for cuts is in our secretarial support. Medical secretaries have a very important role in coordinating care for women that is often undervalued...”***

***“Support staff is not expanding in line with increased referrals – hence the patient experience is greatly below a standard we should be striving for. Clinics are too busy due to trusts not willing to pay for extra clinic time, hence again a poorer service for each patient.”***

Almost a half (47%) of all clinicians said they expect the budget cuts will impact on the services they provide at their hospital at some point in the future.

***“We are being stopped from introducing new treatments due to budget limitations and are increasingly struggling to meet the requirements for weekly chemotherapy within the existing chemotherapy units.”***





### International benchmarking

In the 2009 Target Ovarian Cancer Pathfinder Study, the Advisory Panel said it was important to understand why survival rates for ovarian cancer in the UK appear to lag behind those in other countries. As a result, Target Ovarian Cancer commissioned a feasibility study to determine whether it would be possible to extract data from different countries to make useful and robust comparisons. The feasibility study concluded that it was possible through a high-resolution study, which would involve retrieving data from case notes, rather than just looking at data from cancer registries. Meanwhile the Department of Health announced the International Cancer Benchmarking Partnership Study, which would look at breast, lung, bowel and ovarian cancers across a range of countries including Norway, Sweden, Denmark, parts of Canada and Australia, England, Wales and Northern Ireland.



Target Ovarian Cancer welcomed this study, and shared its findings with the Department of Health. Early results from the study have confirmed that England in particular has low one-year survival rates for ovarian cancer, which is seen as a proxy measure for late diagnosis. For those women who survive at least a year, their five-year survival rates are as good, if not better than elsewhere, implying our treatment and management of women is effective. However there have been several delays to later parts of the study, and aspects of the ovarian cancer element have been changed or dropped (such as measuring GP knowledge), and it is unclear whether the high-resolution element of the study will indeed take place. This is a matter of concern to Target Ovarian Cancer and the Advisory Panel.



Awareness of the International Cancer Benchmarking Partnership Study is low, with just 26% of clinicians having heard of this, and this is despite almost all (96%) of clinicians saying it is important that remedial action is taken to ensure women in the UK have as good a chance of surviving ovarian cancer as women in other countries. By far the biggest proportion of clinicians (55%) believe that tackling earlier diagnosis is the most urgent issue (83% believe remedial action should be taken). 10% believe that targeted treatments are the most important, and a similar proportion believe more radical surgery is most important.



### Role of the multi-disciplinary team (MDT)

The mid-1990s saw the introduction of multi-disciplinary teams for cancer care, in order to bring together specialist skills and knowledge for types of cancer, and to improve decision making, data reporting, and communication not only with patients, but between primary, secondary and tertiary care.

Among those working in gynaecological cancer, multi-disciplinary teams are highly valued with 99% of clinicians agreeing completely or to a large extent that they are important in managing the care of women with ovarian cancer. However a significant minority (30%) of clinicians believe they do not have sufficient time to discuss all the cases they need to. For the majority of clinicians the amount of time available to hold meetings remains unchanged in the last three years (83%).

***“The fact that our MDT meetings do not overrun should not be taken as a sign that there is adequate time. It merely reflects the fact that we have to vacate the room to allow another meeting to take place.”***

### Surgeons

Since the first Pathfinder Study there has been a growing increase in interest in undertaking more radical surgery for women with ovarian cancer. However it has been unclear how widespread this view has been held.

In the 2012 Pathfinder Study, 50% of surgeons agreed that performing more radical surgery would improve the chances of survival for women with ovarian cancer. 25% neither agreed nor disagreed, 17% disagreed, and 8% said they did not know. Over half of the surgeons said their centre was preparing to incorporate more radical surgery into treatment using gynaecological oncology surgeons (22%), other specialist surgeons (such as bowel or upper GI surgeons) (20%), or by allowing more time in theatre (14%). 60% of surgeons believed there would also be a growing role for surgery to treat recurrent ovarian cancer. However the surgeons highlighted barriers to increasing surgery as follows:

Barriers to increasing the amount of radical surgery	%
Access to theatre time	38%
Lack of surgical expertise	18%
Lack of access to other necessary surgical discipline	16%
Impact on recovery time	6%
Access to theatre support staff	0%
Other	22%





### 2012 Advisory Panel comments

The Advisory Panel felt very strongly that the role of the Clinical Nurse Specialist is extremely vulnerable, particularly in the current financial climate and the position has worsened since 2009. However there were positive aspects, such as those areas where nurse-led clinics had been established, and creative ways of working adopted. The panel would like to see a working group established with the Royal College of Nursing, the National Forum of Gynaecological Oncology Nurses and other interested parties to develop a united voice on the value that the CNS role can bring to trusts, giving those trusts who have embraced new ways of working the chance to profile their work and the benefit it has delivered.

In addition the Advisory Panel felt that whilst it had chosen to survey clinicians on a selection of topics that were known to be of interest, in future it would seek to get a more complete picture of clinicians' experiences along the entire care pathway.

### KEY ACTIONS FOR TRUSTS AND NATIONAL BODIES

- Ensure trusts who have successfully worked with CNSs to improve patient experience and departmental efficiency work with Target Ovarian Cancer to provide best practice examples for others to follow
- Ensure that lists of clinicians should be available to all bodies working in the area from the NCRI, NCIN, NCAT to charities to allow more effective dissemination of the Study, its results, and other matters relating to ovarian cancer

### WHAT'S AVAILABLE

- Target Ovarian Cancer's new website for CNSs working in gynaecological oncology [www.CNShub.org.uk](http://www.CNShub.org.uk). It will provide a one stop shop for information on new ways of working, best practice, policy initiatives, resources to help support women with ovarian cancer, and peer to peer support
- Target Ovarian Cancer is launching a working group on the role of the Gynaecological Oncology Clinical Nurse Specialist
- Target Ovarian Cancer have supportive, patient pathway guides available free of charge (Information Standard accredited)
- Target Ovarian Cancer hosts supportive events for women around the UK, working with local CNSs and clinicians [www.targetovariancancer.org.uk/ihaveovariancancer](http://www.targetovariancancer.org.uk/ihaveovariancancer)

# Ovarian cancer factfile



## About ovarian cancer

- Ovarian cancer is the fourth most common cause of cancer death amongst women (after breast, lung and bowel)
- It is the deadliest of all the gynaecological cancers, with deaths from ovarian cancer nearly four times more common than those from cervical cancer
- Each year 7,000 women are diagnosed with ovarian cancer in the UK, and 4,300 women lose their lives
- Most women diagnosed with ovarian cancer are over the age of 50, but it can occur at any age. Around 1,150 women are diagnosed each year under the age of 50
- Age and family history (on either side of the family) are the biggest risk factors

## Survival rates

- UK five-year survival rates are amongst the lowest in Europe at 36%. Matching the best European survival rate would save up to 500 lives per year
- The first results of the Department of Health's International Cancer Benchmarking Study showed that late diagnosis in the UK is a major contributor to its overall poor survival rates
- If diagnosed at the earliest stage, up to 90% of women would survive five years or more

## Late diagnosis

- Three-quarters of women are diagnosed once the cancer has already spread. Only pancreatic cancer has a higher proportion of people diagnosed with late-stage disease

- Women with ovarian cancer are five times more likely to die within a month of diagnosis than women with breast cancer (11% vs. 2%)
- Almost a third of women with ovarian cancer (32%) are diagnosed through Accident and Emergency
- The average GP will see a case of ovarian cancer once every five years. In comparison they will see one breast cancer case each year

## Treatments

- There have been no new life-extending treatments in over 20 years
- There is an urgent need for progress. If we matched the achievements in breast cancer in the last 20 years, over 3,000 more women would survive each year
- Most women develop resistance to the chemotherapy treatments – there is an urgent need for new life extending treatments
- There is chronic underfunding for research in comparison with some other common cancers

## National guidance

- The National Institute of Health and Clinical Excellence produced guidance on 'The recognition and initial management of ovarian cancer' in 2011. It provides the most up to date evidence around the symptoms of the disease and the diagnostic process [www.nice.org.uk/CG122](http://www.nice.org.uk/CG122). In 2012 NICE published the Ovarian Cancer Quality Standard <http://guidance.nice.org.uk/QS18>



# About Target Ovarian Cancer

**Target Ovarian Cancer is the national ovarian cancer charity working to save lives and help women diagnosed live their lives to the full, wherever they are in the UK.**

**We do this by:**

- Improving early diagnosis
- Finding new treatments
- Providing support for women

**Our work is distinctive because:**

- We have a programme of work across the UK
- We reach out directly to women, researchers and health professionals
- We tackle the three biggest barriers to progress - late diagnosis, no new treatments, and the isolation so often felt by women with ovarian cancer

**We invest in:**

- Improving early diagnosis through training women and GPs, and campaigning for a nationally-led programme to improve symptoms awareness
- Directly funding national research into new treatments for ovarian cancer
- Running a UK-wide support programme for all women affected by ovarian cancer, via events, publications and information

**Contact us**

Target Ovarian Cancer  
30 Angel Gate  
London EC1V 2PT

Tel 020 7923 5470  
[info@targetovarian.org.uk](mailto:info@targetovarian.org.uk)  
[www.targetovariancancer.org.uk](http://www.targetovariancancer.org.uk)



# Target Ovarian Cancer

## – free resources for women



### Events - Being Together days

Positive informal day-long events around the UK which bring together women affected by ovarian cancer in their local area. Each Being Together event offers a chance for women to socialise outside hospital, learn about local services and take part in wellbeing workshops such as relaxation or getting the most out of life. Target Ovarian Cancer works with local CNSs to invite women and shape the day.

### Events - Let's Talk awareness raising training

For new or experienced ovarian cancer awareness raisers our training days give the ideas and skills needed to make awareness raising a great success.

### Online resources for women

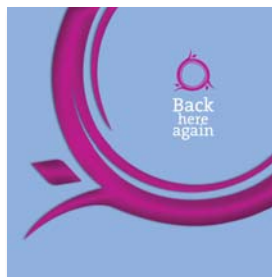
- Information about ovarian cancer
- Advice on living with ovarian cancer
- Regular series of 'Ask the Expert' featuring women's queries on a range of issues
- Search tool for local support groups
- Clinical trials information centre

### Publications



#### What happens next?

For women who have recently found out they have ovarian cancer, our guide gives information and offers support for the months ahead.



#### Back here again

For women who have recently found out that they have ovarian cancer again, our guide has information and offers support in the months ahead. It has a special pull out section for family and friends.



#### Looking after me

For women living with terminal ovarian cancer. This, like all our guides, has been written with the help of women living with the challenges of this situation, and we hope it will help them to live their life to the full.

To order copies of our publications or find out more about our resources for women call **020 7923 5470** or email **info@targetovarian.org.uk**



All our materials are Information Standard accredited.

# References

---

## Page 4

1. [http://www.ncin.org.uk/publications/data\\_briefings/routes\\_to\\_diagnosis.aspx](http://www.ncin.org.uk/publications/data_briefings/routes_to_diagnosis.aspx)
2. Sir David Nicholson, Chief Executive of the NHS 2010

## Page 8

1. [www.nice.org.uk/cg122](http://www.nice.org.uk/cg122)

## Page 9

1. The Ovarian CAM was developed by Target Ovarian Cancer, The Eve Appeal, and Ovacome. It is based on a generic CAM developed by Cancer Research UK, University College London, Kings College London and Oxford University in 2007-08 [http://www.cancerresearchuk.org/prod\\_consump/groups/cr\\_common/@nre/@hea/documents/generalcontent/cr\\_043272.pdf](http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@hea/documents/generalcontent/cr_043272.pdf)

## Page 14

1. <http://www.dh.gov.uk/health/2012/08/cancer-experience-survey/>

## Page 16

1. <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/nhs-constitution-interactive-version-march-2012.pdf>

## Page 18

1. <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/nhs-constitution-interactive-version-march-2012.pdf>




## **Bridging the gap: Improving outcomes for women with ovarian cancer**

### **Results from the Target Ovarian Cancer Pathfinder Study (2012)**

All rights reserved. If you wish to reproduce any part of this publication, in any way, you must request permission from Target Ovarian Cancer and acknowledge Target Ovarian Cancer as the source.

ISBN 978-0-9571248-5-1

 Target Ovarian Cancer  
30 Angel Gate  
London, EC1V 2PT

 020 7923 5470

 [info@targetovarian.org.uk](mailto:info@targetovarian.org.uk)

 [www.targetovariancancer.org.uk](http://www.targetovariancancer.org.uk)

 [www.facebook.com/TargetOvarianCancer](https://www.facebook.com/TargetOvarianCancer)

 [@targetovarian](https://twitter.com/targetovarian)

© Target Ovarian Cancer 2013

Target Ovarian Cancer is a company limited by guarantee, registered in England and Wales (No. 6619981). Registered office: 30 Angel Gate, London EC1V 2PT. Registered charity numbers: 1125038 (England and Wales) and SC042920 (Scotland).