



# Pathfinder 2016



Transforming futures  
for women with  
ovarian cancer





**20%**

of women able to name bloating as a symptom of ovarian cancer

**4%**

of women very confident they can spot a symptom of ovarian cancer



**41%**

of women visit their GP three times or more before being referred for diagnostic tests



**44%**

of GPs wrongly believe symptoms only present in the later stages of the disease

**63%**

of women with ovarian cancer are given written information at the point of diagnosis



**46%**

of nurses feel their cancer centre or unit has enough nurses to care for all the women treated there



**66%**

of women with ovarian cancer are prepared to travel to take part in clinical trials



**80%**

of women with ovarian cancer experience mental ill health

## **Awareness among women in the general population**

The Ovarian Cancer Awareness Measure was used to measure awareness of ovarian cancer among women in the general population.<sup>1</sup>

Telephone interviews were carried out between 5 February and 1 March 2016. A random digit dialling sampling approach was used including 25 per cent mobile numbers to reduce any age bias (as younger women are less likely to live in accommodation with a landline). In total 1343 women took part in the survey.

The research was carried out by Opinion Leader who are a member of the Interviewer Quality Control Scheme and have Market Research Quality Standards Association accreditation. All research was conducted by their in-house telephone research team.

## **Knowledge and experience among practicing GPs**

A survey of practicing GPs across the UK was used to measure GP awareness and experience of ovarian cancer.

The survey was carried out online between 26 February and 5 March 2016 and in recognition of their time, GPs were paid a small fee to participate. The sample was taken from the membership of Doctors.net which is free and gives doctors access to forums, Continuous Professional Development and wider resources. Doctors.net is accessed by approximately one in three UK GPs. The opportunity to take part was shown to GPs currently practicing in the UK on the landing page following sign-in and in the final few days of the survey appeared as a pop-up alert to encourage final completions. To ensure a geographically representative sample across the UK the survey was closed in each region as its respective quota was filled. A total of 504 GPs took part in the survey.

The research was carried out by medeConnect whose research audience spans a wide range of health professionals both in the UK and globally. It was carried out as a bespoke survey.

## **Women with ovarian cancer**

The survey of women with ovarian cancer asked women about their experiences from symptoms, through to diagnosis and treatment. The survey was open to all women with ovarian cancer diagnosed since 2010 (approximately 16,000) currently living in the UK.<sup>2</sup>

The survey ran online from 1 April to 14 August 2016. It was promoted through Target Ovarian Cancer's website, digital mailing list and social media. Promotional postcards were sent to every cancer unit and centre across the UK and hard copies were mailed to those women on Target Ovarian Cancer's database in Northern Ireland, Scotland and Wales who did not receive the digital mailing, to help increase the response rate in these nations. In total 396 women with ovarian cancer took part in the survey.

## Nurses working with women with ovarian cancer

The survey of nurses working with women with ovarian cancer asked about their experiences of caring for women and the support they are able to provide.

The survey ran online from 25 April to 14 August 2016. It was promoted through Target Ovarian Cancer's network of Gynaecological Oncology Clinical Nurse Specialists, promoted at the annual conference of the National Forum of Gynaecological Oncology Nurses and via the Pathfinder Advisory Panel. In total 41 nurses took part in the survey.

The majority of nursing support for women with ovarian cancer is provided by Gynaecological Oncology Clinical Nurse Specialists or Advanced Nurse Practitioners - for simplicity, we have referred to Clinical Nurse Specialists (CNSs) or nurses throughout this report.

## Family and friends

The survey of the family and friends of women with ovarian cancer asked about their experience and the impact on them of their relative's or friend's diagnosis. For those women no longer with us, it also provided a chance to capture experiences of the care and support provided to women with ovarian cancer right at the end of their life.

The survey ran online from 4 May to 14 August 2016. It was promoted through Target Ovarian Cancer's website, digital mailing list and social media. This was the first time a survey capturing the experiences of family and friends had been included in Pathfinder and in total 189 people took part.

This data has been used carefully in the context of reporting the experiences of the women with ovarian cancer being cared for, recognising that family members and friends may not have been aware of all aspects of a woman's treatment and care. These findings are therefore presented as exploratory only.



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**Ovarian cancer is the deadliest of gynaecological cancers with over 4,000 women dying from the disease in the UK each year.<sup>3</sup> Although survival rates have improved in recent years, they still lag behind those of other countries and while it is true that overall more people now survive cancer than die from it, this is far from the case when it comes to ovarian cancer.<sup>4</sup>**

Target Ovarian Cancer was founded in 2008 to change this. One of the charity's earliest acts was to carry out the first Pathfinder, to identify what was working and what needed to change.

Since that first Pathfinder we have seen:

- National guidelines setting out the diagnostic and initial pathway for women with possible symptoms of ovarian cancer.
- The piloting of government funded symptoms awareness campaigns for ovarian cancer.
- New drugs for the treatment of ovarian cancer, particularly olaparib (Lynparza®) and bevacizumab (Avastin®).
- The introduction of genetic testing for all women with ovarian cancer who are at risk of carrying a BRCA mutation.

Pathfinder is unique in having charted the wider ovarian cancer landscape throughout this time, gauging women's experiences, public awareness, GP knowledge and clinical practice.

Among other issues, the two previous Pathfinders identified difficulties accessing diagnostic tests, low GP awareness of the symptoms of ovarian cancer and poor access among women with ovarian cancer to clinical trials. Target Ovarian Cancer responded by campaigning for, and securing, a government commitment on diagnostic tests. The charity invested in GP education, with over one in three GPs having now undertaken one of Target Ovarian Cancer's accredited training modules. Finally, the charity launched the award winning Ovarian Cancer Clinical Trials Information Centre to ensure all women, wherever they live in the UK, have access to reliable information on the latest trials.

Pathfinder 2016 shows real improvement in certain areas. Although still low, there has been a noticeable rise in awareness of the key symptom of bloating. Long held myths around the challenges of diagnosing ovarian cancer, including the mistaken belief that it is a 'silent killer', are slowly being broken down among GPs. There is now much better access to diagnostic tests and more women are receiving written information about their diagnosis and treatment.

This progress is also reflected in the wider statistics and reporting, which has improved significantly with the formation of the National Cancer Registration and Analysis Service and its predecessor the National Cancer Intelligence Network. Crucially, the number of women with ovarian cancer diagnosed following an emergency presentation (typically Accident and Emergency) has fallen from 31 per cent at the time of the first Pathfinder to 26 per cent in the most recent figures.<sup>5</sup>

Finally, we can see the change in women's chances of surviving this disease. Of those women diagnosed in 2016, 500 more will survive five years or longer than when we commissioned the first Pathfinder in 2009.<sup>6</sup>

However, much more needs to be done, urgently, and Pathfinder 2016 shows where action is required.

### Diagnosing women sooner

If diagnosed at the earliest stage (Stage I), up to 90 per cent of women with ovarian cancer will survive five years or more, yet currently nearly two thirds of women are diagnosed once the cancer has already spread (Stage II-IV).<sup>7,8</sup>

Improving early diagnosis requires a two pronged approach. The first is ensuring women know the symptoms to look out for; the second is that GPs have the knowledge and the support to refer women promptly.

Awareness of bloating as a symptom of ovarian cancer has risen among women since the first Pathfinder, but this is beginning to level off with just 20 per cent able to name bloating as a symptom of ovarian cancer when asked in 2016.

Among GPs, attitudes towards ovarian cancer are shifting, but 44 per cent continue to falsely believe that symptoms only present in the later stages of the disease. In contrast, of the women responding to our survey, of those diagnosed with either Stage I or Stage II (early stage) ovarian cancer, 86 per cent experienced at least one of the symptoms recognised in national guidelines, showing it is a far from silent disease.

Other cancers have seen significant improvements following the introduction of national screening programmes. However, with the recent findings of the UK Collaborative Trial of Ovarian Cancer Screening this now looks unlikely in the immediate future for ovarian cancer.<sup>9</sup>

If we are to diagnose more women sooner, action is needed on improving awareness of the symptoms of ovarian cancer among women in the general population and GP training.

## Action

National awareness campaigns that include the symptoms of ovarian cancer in England, Northern Ireland, Scotland and Wales to ensure women know the symptoms to look out for and the importance of going to their GP.



## Action

Target Ovarian Cancer to double the number of GPs who have completed accredited training on ovarian cancer.



## Supporting women through treatment

While the vast majority of women diagnosed with ovarian cancer are assigned a Clinical Nurse Specialist (CNS), nurses are becoming increasingly stretched and unable to spend the time they want with women.

Large numbers of women reported unmet medical needs, including managing the side effects of chemotherapy, and very few women are receiving any support around needs such as body image and intimacy. 37 per cent of nurses are unable to fully meet all of women's medical needs, such as helping with symptom control, and 53 per cent are unable to meet women's wider needs.

Only 36 per cent of women with ovarian cancer said anyone involved in their treatment had talked about their mental health with them. This is despite the fact that 80 per cent of women reported experiencing mental ill health as a result of their diagnosis.

If all women are to receive the support they need through treatment, investment is needed in CNSs to enable them to spend the time they want, and that women need, supporting women with ovarian cancer.

### Action

For the NHS to honour the commitment in the new cancer strategy in England for all people with cancer to have access to a Clinical Nurse Specialist and for an equivalent commitment to be made in Northern Ireland, Scotland and Wales.



### Action

Target Ovarian Cancer to invest in new services and support to help meet the wider needs, including mental health and sexuality, of women with ovarian cancer.



## Supporting women through recurrence

53 per cent of women with ovarian cancer reported that no one discussed the possible symptoms of recurrent ovarian cancer with them. Of those women whose cancer had returned, fewer received written information than when initially diagnosed and women were less likely to have their case discussed by the Multi-Disciplinary Team responsible for their treatment.

This reflects the lack of guidelines for recurrent ovarian cancer for the majority of women with ovarian cancer living in the UK. While guidelines in Scotland cover treatment for recurrent disease, those covering the remainder of the UK address only the initial diagnosis, surgery and first round of chemotherapy treatment.

Action is needed to develop a clear treatment pathway for all women with recurrent ovarian cancer wherever they live in the UK.

## Action

The National Institute for Health and Care Excellence to develop clinical guidelines for recurrent ovarian cancer.



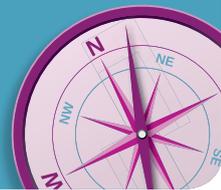
### Improving treatment

Pathfinder helps measure women's experiences, and maps out both challenges and progress in awareness and diagnosis. However, clinical data is needed to map women's journeys through treatment, to help demonstrate what works and what doesn't and where standards are being met and where they are not.

To ensure all women are receiving the right treatment at the right hospital, we need an ovarian cancer audit in each of the four nations.

## Action

An ovarian cancer audit in England, Northern Ireland, Scotland and Wales mapping the diagnostic and treatment pathway for all women with ovarian cancer.



Finally, while not something directly addressed in Pathfinder itself, if we are to see more and better treatment options available to women with ovarian cancer, we also need to see more investment in research. While Target Ovarian Cancer has invested nearly one million pounds in research in recent years, overall levels of investment have fallen, jeopardising the treatments of tomorrow.<sup>10</sup>

Pathfinder 2016 shows that steps have been taken, but we are still only at the start of the journey we all must go on to achieve the transformation in diagnosis and treatment of ovarian cancer that is so clearly needed.

### Professor Michael Peake

Chair, Pathfinder 2016 Advisory Panel  
Clinical Lead for the National Cancer Registration and Analysis Service



### Annwen Jones

Chief Executive, Target Ovarian Cancer





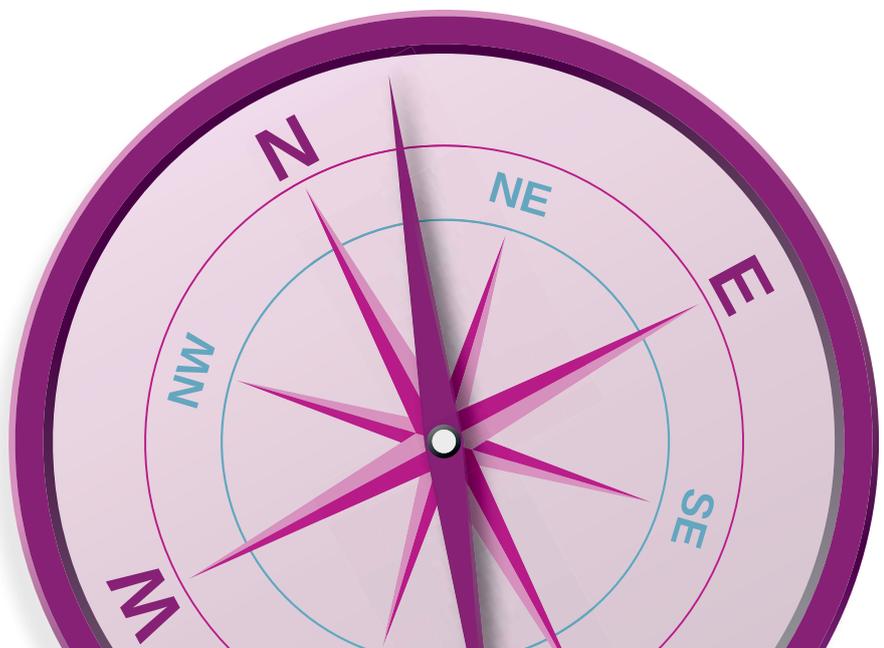
# Introduction

**Target Ovarian Cancer carried out its first Pathfinder in 2009. The purpose of the Pathfinder studies is to establish what is working and what needs to improve in order to transform survival and quality of life for women diagnosed with ovarian cancer. Pathfinder enables Target Ovarian Cancer, policy makers and those working in the field of ovarian cancer more widely to identify priorities for change and gauge progress to date.**

This is the third Pathfinder and this report is based on five different surveys:

- Women in the general population
- Women with ovarian cancer
- Practicing GPs
- Nurses working with women with ovarian cancer
- Family and friends

The report is structured around the patient pathway. It begins with awareness and diagnosis, before moving on to treatment and support. It also has sections looking at genetics, clinical trials and mental wellbeing and body image to present a more complete picture.



# Awareness of symptoms

**By knowing the symptoms to look out for, women are more likely to visit their GP sooner, increasing their chances of being diagnosed earlier.**

The key symptoms of ovarian cancer are:

- Persistent abdominal distension (bloating tummy)
- Pelvic or abdominal pain (tummy pain)
- Feeling full (early satiety) and/or loss of appetite (always feeling full)
- Increased urinary urgency and/or frequency (needing to wee more)

Symptoms can also include:

- Unexplained weight loss
- Unexplained fatigue
- Unexplained changes in bowel habit<sup>11,12</sup>

Women in the general population were asked to say which symptoms they think might be linked to ovarian cancer in every Pathfinder to date. Table 1 shows awareness over time for the four primary symptoms.

**Table 1. Ability of women in the general population to name one of the four main symptoms of ovarian cancer (unprompted)**

<b>Pathfinder</b>	<b>Persistent bloating</b> (per cent)	<b>Pelvic or abdominal pain</b> (per cent)	<b>Feeling full/ loss of appetite</b> (per cent)	<b>Increased urinary urgency / frequency</b> (per cent)
2009	9	24	1	1
2012	17	28	2	1
2016	20	20	3	2

While awareness of loss of appetite and urinary frequency as symptoms has remained low and awareness of the symptom of pelvic or abdominal pain has fluctuated, awareness of bloating as a symptom has gradually risen, although is now levelling off. Unprompted awareness of any of the symptoms has never risen above 30 per cent.

Making sure women know the symptoms to look out for is the first step in ensuring more women are diagnosed sooner, yet at the moment too few women know the warning signs of ovarian cancer.

## Low and often misplaced confidence

Women were asked how confident they were at spotting a symptom of ovarian cancer and 27 per cent said they felt confident, including only four per cent who were very confident they could spot a symptom. This is little changed from 2009 and 2012.

However, as Table 2 shows, this confidence is often misplaced, with almost half of those women confident they could spot a symptom unable to correctly identify a single one.

**Table 2. Ability of those confident at spotting a symptom of ovarian cancer to name at least one recognised symptom**

How confident are you that you would notice an ovarian cancer symptom?	Can name any recognised symptom (per cent)	
	Yes	No
Not at all confident	25	75
Not very confident	38	62
Fairly confident	52	48
Very confident	53	47

Symptoms: persistent abdominal distension (bloating), feeling full and/or loss of appetite, pelvic or abdominal pain, increased urinary urgency and/or frequency, unexplained weight loss, unexplained fatigue and unexplained changes in bowel habit

## Confusion with cervical cancer

More women now understand the distinction between cervical and ovarian cancer. While in 2012, 47 per cent of women believed that cervical screening also detects ovarian cancer, by 2016 this had fallen to 31 per cent. That still leaves nearly one in three women wrongly believing that cervical screening also detects ovarian cancer.

The confusion between ovarian and cervical cancer is reflected in awareness of symptoms, with 19 per cent of women saying they thought bleeding might be a symptom of ovarian cancer. Unusual bleeding is a key symptom of cervical cancer.





**Over a quarter of women with ovarian cancer are diagnosed through Accident and Emergency and just one in three women are diagnosed with Stage I disease (where survival is highest).<sup>13,14,15</sup>**

National guidelines set out how GPs should assess and refer women with symptoms that could be ovarian cancer. GPs should start by discussing the symptoms experienced by women and their frequency before carrying out a pelvic examination to check for a mass or ascites (fluid in the abdomen).

If a mass or ascites are found, GPs should make an urgent (two week wait) referral to a gynaecological oncologist.

In all other cases GPs should refer women for a CA125 blood test. If this shows raised levels of the CA125 protein, then women should be referred for an ultrasound (transvaginal and abdominal). (Except in Scotland where both the blood test and ultrasound are carried out at the same time.) If a mass is detected, women should be referred on to a gynaecological oncologist.<sup>16,17</sup>

Previous Pathfinders have found many mistaken beliefs held by GPs in regards to ovarian cancer. These include believing that it is a ‘silent killer’ and that symptoms only present in late stage disease. Of those women who visited their GP prior to diagnosis, 90 per cent experienced recognised symptoms and this included 86 per cent of those diagnosed with early stage disease (Stage I or II).

Table 3 includes both the most recent results, and the findings from previous Pathfinders. It shows that GPs’ understanding of ovarian cancer is increasing, but that much remains to be done.

**Table 3. GP beliefs regarding presentation of symptoms of ovarian cancer**

Pathfinder	GPs saying symptoms only present in the later stages of the disease (per cent)	GPs saying ovarian cancer is a silent killer (per cent)
2009	79	96
2012	67	91
2016	44	77

## Going to the GP

Among those women who experienced symptoms, 36 per cent went to see their GP within a month of these starting, unchanged from the previous Pathfinder and down slightly on Pathfinder 2009.

60 per cent of women said that they felt their GP took their concerns seriously. Many women faced multiple visits to their GP before being referred for the tests that led to their diagnosis, although as Table 4 shows, this number is gradually falling.

**Table 4. Women visiting their GP three times or more before being referred for diagnostic tests**

Pathfinder	Women visiting their GP three times or more before being referred for diagnostic tests (per cent)
2009	54
2012	49
2016	41

The latest findings are broadly comparable to the National Cancer Patient Experience Survey data for 2015, which found 33 per cent of women diagnosed with ovarian cancer reporting visiting their GP three times or more before being referred for diagnostic tests.<sup>18</sup> The average across all cancers is 24 per cent of patients having to visit their GP three times or more prior to referral, meaning women with ovarian cancer are more likely to face repeat visits to their GP.<sup>19</sup>

## Misdiagnosis

46 per cent of women were initially referred for tests for something other than ovarian cancer. Guidelines are clear that a possible diagnosis of ovarian cancer should be considered for any woman aged 50 or over presenting with symptoms that suggest irritable bowel syndrome (IBS).<sup>20</sup> Of those women responding to Pathfinder 2016 aged 50 or over who visited their GP to discuss symptoms, 21 per cent were told they might have IBS.

In eight per cent of cases among women visiting their doctor with symptoms, GPs suggested their symptoms might be down to mental ill health.

## Diagnostic tests

Cancer strategies in all four nations place an emphasis on early diagnosis and timely diagnostic testing.<sup>21</sup>

Of those GPs responding to our survey, 99 per cent reported they had direct access to CA125 blood tests and 97 per cent direct access to non-obstetric ultrasound in cases of suspected ovarian cancer. This is in contrast to 2009, when more than one in ten GPs reported being unable to directly access non-urgent transvaginal ultrasounds (one of two types of ultrasound scans, the other being abdominal, used in the diagnosis of ovarian cancer).

Despite the improvement in access to diagnostic tests, Table 5 shows there is little change in the overall time it is taking for women to receive a diagnosis compared to previous Pathfinders.

**Table 5. Time taken from first visiting GP to receiving diagnosis**

Pathfinder	Less than one month (per cent)	One to three months (per cent)	Over three months (per cent)
2009	23	32	45
2012	21	30	47
2016	27	29	45

Numbers may not total 100 due to a small number of patients unsure of time taken to receive a diagnosis.



**41 per cent of women visit their GP three times or more before being referred for diagnostic tests.**



**There are several genetic faults or mutations linked to ovarian cancer. Of greatest significance is a mutation in the BRCA1 or BRCA2 gene; this mutation accounts for around 13 per cent of all cases of ovarian cancer.<sup>22</sup> The risk of developing ovarian cancer is two per cent for women generally, but rises to 30-50 per cent for women with a BRCA1 mutation and 10-25 per cent for women with a BRCA2 mutation.<sup>23</sup> BRCA mutations can pass down either the mother's or father's side of the family. If a parent has the BRCA mutation, there is a 50 per cent chance they pass it on to their child.**

Awareness of the significance of genetics remains low. Among women in the general population, 25 per cent think genetics might be a factor in developing ovarian cancer and 44 per cent of women with ovarian cancer are aware that there might be a genetic link.

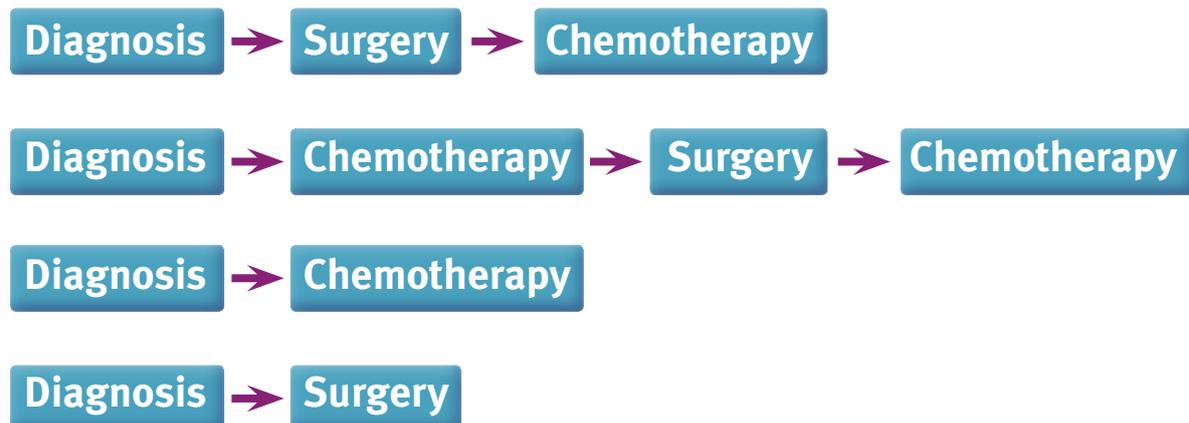
Among GPs, there is high awareness (93 per cent) of the importance of family history on the mother's side, but much lower awareness of the importance of family history on the father's side, with just 38 per cent saying this mattered.

New guidance means that nearly all women with ovarian cancer are now eligible for genetic testing.<sup>24</sup> 86 per cent of women with ovarian cancer felt that all women with ovarian cancer who are offered genetic testing should be offered counselling before giving consent to go ahead with the test. In contrast, of those offered genetic testing, only 61 per cent were given counselling to help them decide whether they would like to be tested.

**Only 38 per cent of GPs  
are aware that family  
history on the father's  
side is important.**

# Starting treatment

Women diagnosed with ovarian cancer are offered a combination of surgery and chemotherapy, or, in a very few cases, surgery or chemotherapy alone.



Guidelines require all women diagnosed with ovarian cancer to be offered information, including written information, about treatment.<sup>25</sup> While gaps remain, notably around the provision of written information at the point of diagnosis and prior to surgery, tables 6 and 7 show that there has been a steady improvement in the way diagnosis and treatment is explained to women and, to a lesser extent, the provision of written information since the first Pathfinder in 2009.

**Table 6. Women reporting their diagnosis and treatment was explained to them in a way they could understand**

Pathfinder	Diagnosis explained in a way women could understand (per cent)	Surgery explained in a way women could understand (per cent)	Chemotherapy explained in a way women could understand (per cent)
2009	76*	65**	72**
2012	62*	73**	69**
2016	82	93	96

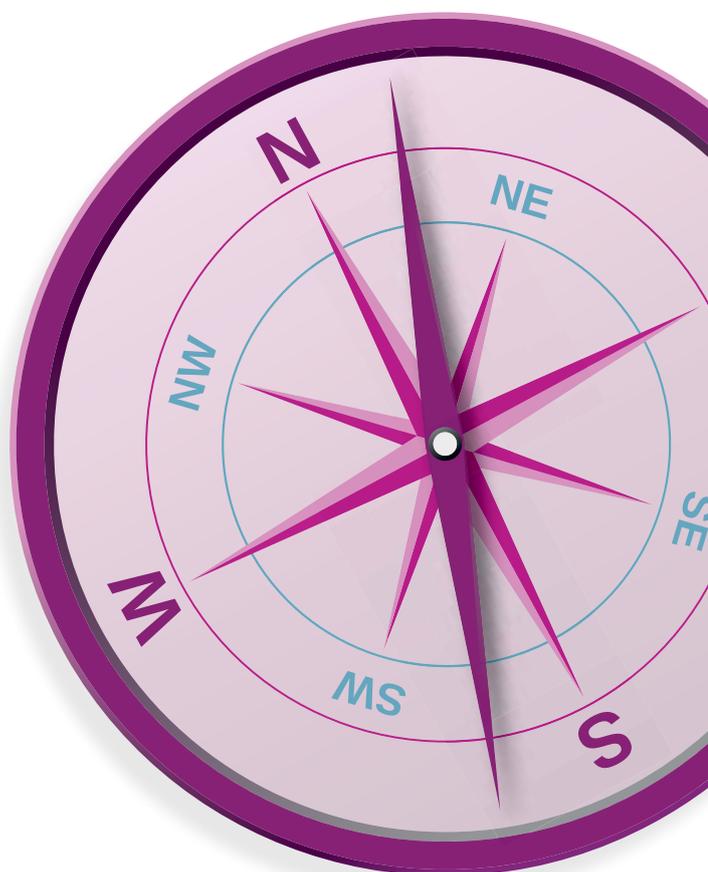
\*In 2009 and 2012 women were asked if they were given all the information they needed to answer any questions they had

\*\*In 2009 and 2012 women were asked if they were able to get answers they could understand to their questions about surgery and chemotherapy.

**Table 7. Women reporting they were provided with written information at diagnosis and during treatment**

Pathfinder	Written information at point of diagnosis (per cent)	Written information before surgery (per cent)	Written information before chemotherapy (per cent)
2009	45	48	82
2012	65	60	76
2016	63	68	95

**63 per cent of women with ovarian cancer are given written information at the point of diagnosis.**





**Clinical trials offer women the opportunity to access new cancer drugs, improve understanding of the disease and treatment options, and access the highest quality care. Research shows that those taking part in clinical trials have improved survival rates, regardless of whether they receive the new treatment or the standard treatment.<sup>26</sup>**

Among women with ovarian cancer, 33 per cent said someone had asked them if they would like to join a clinical trial. Table 8 shows this has changed little since the first Pathfinder in 2009.

**Table 8. Number of women with ovarian cancer talked to about, participating and interested in clinical trials**

<b>Pathfinder</b>	<b>Women talked to about clinical trials (per cent)</b>	<b>Women taking part in clinical trials (per cent)</b>	<b>Women not on a trial who would like to join one (per cent)</b>
2009	39	24	n/a
2012	30	20	n/a
2016	33	25	55

This broadly corresponds to the National Cancer Patient Experience Survey, where 38 per cent of women with ovarian cancer reported that someone had discussed taking part in cancer research.<sup>27</sup> Findings also showed that women were happy to travel to take part in the latest trials, with 66 per cent of those wanting to take part in clinical trials prepared to travel to another hospital to do so.

When asked about their reasons for wanting to take part in clinical trials, 73 per cent of women with ovarian cancer said they felt it was important to take part in trials so knowledge and treatment can advance.

**Clinical Nurse Specialists (CNSs) are there to act as the main contact point for women with ovarian cancer, oversee their general care and offer advice and support. Access to a CNS has risen over time, as shown in Table 9.**

**Table 9. Women with ovarian cancer reporting access to a Clinical Nurse Specialist**

<b>Pathfinder</b>	<b>Women reporting access to a Clinical Nurse Specialist (per cent)</b>
2009	84
2012	89
2016	93

Of the nurses surveyed in 2016, 90 per cent said all women at their hospital were assigned a specialist nurse and the latest National Cancer Patient Experience Survey reinforces this with 93 per cent of women with ovarian cancer reporting being given the name of a CNS.<sup>28</sup>

When asked about the level of support they were able to provide women, only 46 per cent of the nurses responding to our survey felt their cancer centre or unit has enough nurses to care for all the women being treated there. The impact of this can be seen in nurses' ability to meet the needs of women in their care with only 63 per cent saying they were able to meet all the medical needs of women, such as symptom control.

Women with ovarian cancer report significant levels of unmet needs. Just 58 per cent of those women needing support managing ascites (a build-up of fluid in the abdomen) had received it. Of those experiencing nausea, a common chemotherapy side effect, 69 per cent had received help and of those needing help with pain management, just 55 per cent had received this. This is comparable to the National Cancer Patient Experience Survey which found that just 60 per cent of women with ovarian cancer said there were always enough nurses on duty.<sup>29</sup>

It's a similar scenario in relation to non-medical needs with only 48 per cent of CNSs reporting being able to meet women's broader needs such as mental wellbeing, or issues like body image and sexuality. Treatment can have a huge impact on sex and intimacy, but just 12 per cent of women with ovarian cancer said anyone involved in their treatment had talked to them about this. Of those who needed it, just 24 per cent had received support with early onset menopause brought on by their treatment.

Nurses also reported difficulties in referring women for palliative care with just 54 per cent always able to refer women.

# Mental wellbeing & body image

**Aside from the physical implications of a diagnosis of ovarian cancer, having cancer and the treatment involved can impact on a woman's mental wellbeing and affect her body image and confidence.**

## **Mental wellbeing**

80 per cent of women with ovarian cancer said they had experienced mental ill health (including depression, anxiety, stress, low mood and mood swings) since being diagnosed with ovarian cancer. In contrast, just 36 per cent of women said anyone involved in their treatment had discussed their mental wellbeing.

## **Body image and sexuality**

Many women struggle with their body image post treatment and with regaining sexual intimacy. 69 per cent of women with ovarian cancer said they had experienced a loss of self esteem, 73 per cent of women reported difficulties with intimacy and 84 per cent reported a lower sex drive.

**80 per cent of women with ovarian cancer experience mental ill health.**



# Recurrence

**Many women are not having possible symptoms of recurrent ovarian cancer discussed with them after completing treatment. Among women with ovarian cancer, 53 per cent said no one talked them through the symptoms of recurrent ovarian cancer and 63 per cent of nurses said they don't always have time to do this. 51 per cent of women with ovarian cancer said they needed support coping with the fear of recurrence.**

For those women who do have a recurrence, many are not receiving the same level of support as when first diagnosed. As Table 10 shows, while women are being given time to discuss their diagnosis, they are less likely to have access to a Clinical Nurse Specialist, less likely to receive information and their case is less likely to be discussed at Multi-Disciplinary Team meetings (when all health professionals involved in a woman's care discuss her treatment).

**Table 10. Differences between experience of women diagnosed with recurrent ovarian cancer and women receiving an initial diagnosis**

	<b>Enough time to discuss their diagnosis</b> (per cent)	<b>Access to a Clinical Nurse Specialist</b> (per cent)	<b>Given written information at point of diagnosis</b> (per cent)	<b>Cases always discussed at Multi-Disciplinary Team meetings</b> (per cent)
Women first diagnosed	70	93	63	100
Women diagnosed with recurrent ovarian cancer	82	83	33	51



# Care in the final days

**The experiences of women right at the end of life are often not captured, so we asked family and friends to share women's experiences of being given a terminal diagnosis and care in the final few months of their life. This part of the survey is exploratory and findings are indicative only, caveated by the fact that respondents are not always reporting first-hand experience.**

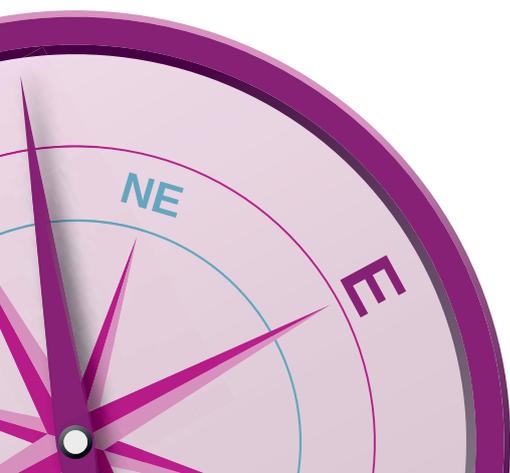
We asked if a terminal diagnosis had been openly discussed by health professionals, and while for the majority of respondents it had, 19 per cent of immediate family members said this was never raised.

Women received a mix of palliative care to help manage pain and relieve symptoms, but also more holistic support including massage and aromatherapy.

When asked if women had been offered a choice of where to spend their last few days, 24 per cent of relatives again said this had not been discussed.

These are very early findings. They suggest that most women are receiving the care and support they and their family need at the end of life but a small number are not, which has a devastating impact on those women and their families.

**33% of women with recurrent ovarian cancer are given written information at the point of diagnosis.**







# Conclusions

**The findings in the preceding pages set out where progress has been made but they also show where more remains to be done. Below are the actions that must be taken if we are to see the transformation in awareness, diagnosis and treatment of ovarian cancer so desperately needed.**

## Awareness

The increase in unprompted awareness of the key symptom of bloating since the first Pathfinder is to be welcomed and is a testament to the work that has taken place to date in raising awareness.

However, overall awareness levels remain low. The first step in ensuring more women are diagnosed earlier and have the best possible chance of survival is making sure they know the symptoms to look out for and the importance of acting on these.

### Action

National awareness campaigns that include the symptoms of ovarian cancer in England, Northern Ireland, Scotland and Wales to ensure women know the symptoms to look out for and the importance of going to their GP.



## Diagnosis

Women still have to make multiple visits to the GP before being referred for diagnostic tests. This figure has consistently improved since the first Pathfinder in 2009, but still lags behind other cancers. A large number of women also continue to be referred for tests for something other than ovarian cancer.

### Action

Trials of patient self-referral for diagnostic tests, as committed to in the latest cancer strategy in England, to include ovarian cancer.



### Action

Target Ovarian Cancer to double the number of GPs who have completed accredited training on ovarian cancer.



## Genetics

Both among the general population and women with ovarian cancer, awareness of the significance of genetics and family history remains low. While GPs appreciate the importance of family history on the mother's side, far fewer are aware of the equal relevance of family history on the father's side.

## Action

Target Ovarian Cancer to promote information and training for GPs stressing the importance of family history on both sides.



The results of genetic testing have significant implications. It may affect a woman's treatment, she may want to explore preventative surgery and it raises the possibility of other family members carrying the same genetic mutation. It is therefore not surprising that women with ovarian cancer overwhelmingly agreed that all women should be offered counselling prior to undergoing testing.

## Action

A sustainable model of pre-testing counselling, led by genetic services, to be delivered as genetic testing is rolled out across the UK for all women with ovarian cancer at risk of carrying the BRCA gene mutation.



## Treatment

Women's feedback on the way their diagnosis and treatment was explained to them is extremely promising, showing the majority of women are having their treatment explained to them in a clear and accessible manner. Lower numbers, though, reported receiving written information.

Women are presented with a huge amount of information, both at diagnosis and throughout treatment, and written information is vital in ensuring women can access the information they need when they need.

## Action

All women to be provided with written information at the point of diagnosis and at other significant milestones in their care and treatment.



## Action

Target Ovarian Cancer to develop personalised information for women with ovarian cancer reflecting the type of cancer and the stage they are at in their treatment.



## Clinical trials

Clinical trials continue to be discussed with only a minority of patients. This might be related to clinicians' concerns about the suitability of trials or the distances involved.

However, women travel across the country, or indeed across countries, to access the latest trials and it is important all women are aware of the opportunities offered by taking part in clinical trials. In some cases it may be that there are no suitable trials, but discussing this with the woman helps them understand the situation and be better informed about the options available to them.

## Action

For the NHS in England, Northern Ireland, Scotland and Wales to ensure all women with ovarian cancer are given information on clinical trials and how to access them.



## Action

Target Ovarian Cancer to continue to provide patient facing information on clinical trials through its Ovarian Cancer Clinical Trials Information Centre.



## Support

Clinical Nurse Specialists (CNSs) and other nurses involved in the care of women with ovarian cancer do an amazing job, with many going above and beyond to provide the support women and their families need. However, responses from both women and the nurses providing their care show that CNSs are becoming increasingly stretched. Many are struggling to meet the medical needs of women with ovarian cancer and lack the time to provide the support needed around mental health and wider holistic needs. Many even struggle to find the time to talk through the possible symptoms of recurrence. While headline figures suggest the majority of women are in contact with a CNS, the reality shows CNSs are not being given the time to provide women with the care they need.

CNSs are a huge asset to the NHS and it is important they receive the appropriate investment and support so they are able to deliver the care they are committed to.

## Action

For the NHS to honour the commitment in the new cancer strategy in England for all people with cancer to have access to a Clinical Nurse Specialist and for an equivalent commitment to be made in Northern Ireland, Scotland and Wales.



## Action

Development of a new metric, based on the extent to which people with cancer's needs are met, to measure the support delivered by Clinical Nurse Specialists.



## Action

Target Ovarian Cancer to develop resources to help Clinical Nurse Specialists make the case for support for investment in services at their centre or unit.



### Mental wellbeing and body image

Being diagnosed with and treated for ovarian cancer does not just place a physical strain on women, but a mental strain too. Pathfinder 2016 shows a high level of unmet need among women with ovarian cancer in relation to their mental wellbeing.

A large number of women with ovarian cancer also report difficulties with body image and regaining sexual intimacy following treatment.

## Action

Target Ovarian Cancer to invest in new services and support to help meet the wider needs, including mental health and sexuality, of women with ovarian cancer.



### Recurrence

Women diagnosed with recurrent ovarian cancer are less likely to be directly introduced to a CNS than women first diagnosed and less likely to have their case discussed at Multi-Disciplinary Team meetings. This in part reflects a lack of resource but also the lack of a clear pathway for recurrent ovarian cancer in much of the UK; except in Scotland, existing clinical guidelines stop after first-line treatment.

## Action

The National Institute for Health and Care Excellence to develop clinical guidelines for recurrent ovarian cancer.



### Care in the final days

These are tentative findings and based on the recollection of family members and friends rather than women themselves. However, existing patient experience measures are not capturing the experiences of cancer patients right at the end of life. This makes it difficult to assess the quality of care and how services can be further developed. The first step in addressing this is the development of a metric to measure the quality of end of life care.

## Action

Public health bodies in England, Northern Ireland, Scotland and Wales to develop a metric for the quality of end of life care.



### Family and friends

As well as the impact on the individual woman, a diagnosis of ovarian cancer also carries implications for her wider family and friends. It can place a huge emotional burden on women's families and it is important family members and those involved in providing care receive support and counselling as appropriate.

## Action

Family members and carers of women with ovarian cancer to be provided with information on sources of support at the point of diagnosis.



### Measuring progress

To develop our shared understanding of the diagnostic and treatment pathway for ovarian cancer, and better pinpoint where change is needed, an ovarian cancer audit is called for in all four nations. This builds on the recommendations of the Chief Medical Officer in England and the last ovarian cancer audit conducted in Northern Ireland.

## Action

An ovarian cancer audit in England, Northern Ireland, Scotland and Wales mapping the diagnostic and treatment pathway for all women with ovarian cancer.



**The findings in Pathfinder 2016 show the progress that has been made in diagnosing and treating ovarian cancer. While awareness levels are still low, more women do now know the symptoms to look out for, GPs have better access to diagnostic tests and more women with ovarian cancer are being provided with information about their diagnosis and treatment.**

However, it is clear that much remains to be done. Too many women continue to think cervical screening protects them against ovarian cancer and many have a false confidence in their ability to spot the symptoms of ovarian cancer.

Women continue to face repeat visits to their GP before being referred for diagnostic tests and many GPs still falsely believe symptoms only present themselves in the later stages of the disease and continue to be unaware of the importance of family history on both sides of the family.

When it comes to treatment, many women with ovarian cancer are going without support to manage both their medical and wider needs as CNSs are stretched to breaking point. For those women with recurrent ovarian cancer, there is even less support and pitifully few treatment options.

Pathfinder 2016 shows what needs to change if we are to diagnose ovarian cancer earlier and ensure more women receive the support they need as they go through treatment. This, together with investment in research to find the treatments of tomorrow, shows the way forward to transform outcomes for women with ovarian cancer. We must now all commit to following it.

# Thank you

Target Ovarian Cancer would like to thank The Peter Sowerby Foundation whose kind generosity made this research possible.



We would also like to thank all those who took the time to complete the surveys that make up Pathfinder 2016; we could not have done it without you.

## The Pathfinder Advisory Panel

Particular thanks must go to the Pathfinder Advisory Panel, representing all parts of the UK and made up of individuals with a wide breadth of experience, both personal and professional, in ovarian cancer.

### Chair

Professor Michael Peake, Clinical Lead for the National Cancer Registration and Analysis Service, Honorary Professor of Respiratory Medicine, University of Leicester, Honorary Consultant Respiratory Physician, University Hospitals of Leicester and Honorary Professor of Respiratory Medicine, University College Hospital, London

### Members

- Ann Adair, patient advocate
- Christine Mitchell, patient advocate
- Dr Alexandra Cran-McGreehin, relative advocate
- Paul Shagouri, relative advocate
- Dr Ros Glasspool, Chair of the National Cancer Research Institute Ovarian sub-group and Consultant Medical Oncologist at the Beatson West of Scotland Cancer Centre
- Dr Andy Nordin, President of the British Gynaecological Cancer Society and Consultant Gynaecologist at The Queen Elizabeth The Queen Mother Hospital, East Kent
- Professor Debbie Sharp OBE, Professor of Primary Care at Bristol University and member of Target Ovarian Cancer's GP Advisory Board
- Natalie Percival, President of the National Forum of Gynaecological Oncology Nurses and Advanced Nurse Practitioner at the Royal Marsden Hospital, London
- Sarah Burton, Gynaecological Oncology Clinical Nurse Specialist at the Velindre Cancer Centre, Cardiff

This report was written by Rebecca Rennison from Target Ovarian Cancer.

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Ovarian cancer can be devastating. It kills 11 women every single day in the UK and survival rates in the UK are among the worst in Europe. But there is hope – **Target Ovarian Cancer**.

We are the authority on ovarian cancer. We work with women, family members and health professionals to ensure we target the areas that matter most for those living and working with ovarian cancer.

As the UK's leading ovarian cancer charity we work to improve early diagnosis, we fund life saving research and we provide much needed support to women with ovarian cancer. We're the only charity fighting ovarian cancer on all three of these fronts, across all four nations of the UK.



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