

Pathfinder 2022: **Faster, further, and fairer**

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Foreword

Ovarian cancer is the deadliest gynaecological cancer. Over 4,000 women die from the disease in the UK each year.¹ More people now survive cancer than die from it, but this is far from the case when it comes to ovarian cancer.² For too long, ovarian cancer has been left behind.

Target Ovarian Cancer was founded in 2008 to change this. One of the charity's key early priorities was to carry out the first Pathfinder study, which was the first state-of-the-nation research in ovarian cancer to develop an evidence base around this disease, identifying what was working and, critically, what needed to change to drive forward urgently needed improvements in survival and support.

We have now carried out Pathfinder in 2009, 2012, 2016 and 2022, giving us a comprehensive overview of how diagnosis, treatment and support in ovarian cancer have changed over time. In the 14 years since Target Ovarian Cancer was founded, we have seen improvements – but the data from this latest Pathfinder study clearly shows we need to see progress that is faster, further, and fairer if we are to achieve world-class outcomes for everyone affected by ovarian cancer.

Significant achievements since 2016

Since our last Pathfinder report in 2016 there have been significant developments that have had a direct impact on those with ovarian cancer:

- ▶ NHS England is committed to ensuring that three quarters of cancers are diagnosed at an early stage (stage I or II) by 2028. This is vital for ovarian cancer where just one third of women are diagnosed at an early stage.³ We want to see the same commitment across the rest of the UK.
- ▶ In November 2020 and in 2021 we saw the first ever government-funded national awareness campaign featuring ovarian cancer symptoms (bloating and discomfort) with NHS England's *help us, help you* abdominal symptoms campaign after over a decade of campaigning by Target Ovarian Cancer.
- ▶ We have also seen exciting progress in ovarian cancer treatment with the introduction of PARP inhibitors. Alongside this we have seen widespread use of genomic testing offering, for the first time, personalised medicine to those with some forms of ovarian cancer.
- ▶ In partnership, Target Ovarian Cancer has funded the ovarian cancer audit feasibility pilot, which has given us in depth data on the diagnosis and treatment of ovarian cancer in England. The audit highlighted unacceptable variation by age and geographical area as well as opportunities to level up outcomes. As a result of the success of the pilot a government funded audit in England and Wales has been commissioned. This was one of the key recommendations from our 2016 Pathfinder study.
- ▶ All four UK nations have adopted or made commitments to variations of rapid cancer diagnostic pathways for those with vague symptoms.

However, from March 2020 the Covid-19 pandemic had a significant impact across the health service and on ovarian cancer diagnosis and treatment. It is clear that while NHS staff worked incredibly hard to minimise the disruption, we still have some way to go to recover. And as well as recover, now is the time to go further.

Key findings

▶ Awareness

Awareness of ovarian cancer symptoms in the general population has shown some improvement since we first started measuring this in 2009. However, progress has been slow, and we have seen little improvement in the knowledge of feeling full and urinary symptoms. This is compounded by 40 per cent of women wrongly believing that cervical screening detects ovarian cancer.

To tackle this awareness crisis, we need to see widespread government backed symptoms awareness campaigns.

▶ Diagnosis

The faster ovarian cancer is diagnosed, the greater the chance of receiving treatment and the greater the chance of survival. For the first time, we surveyed GP knowledge of symptoms unprompted and found good awareness of the symptoms of bloating and abdominal pain, which is welcome following Target

Ovarian Cancer's investment in GP education programmes. However, similar to the general people population survey, there was less awareness of feeling full and urinary symptoms. We also found delays in both access to diagnostic tests and GPs receiving results, as well as GPs needing more support to interpret test results.

It is vital that existing guidelines are updated to provide GPs with the support they need to identify ovarian cancer as quickly as possible.

► Treatment

Ovarian cancer treatment has changed significantly since 2016 with widespread access to maintenance treatment and greater access to genomic testing. As genomic testing moves at pace it is vital that the consent process empowers patients to make the best choice for them. We also found that the pandemic has had an impact on access to surgery and the opportunity to be involved in clinical trials.

We need to see all those who would benefit from surgery able to access it; and clinical trials should be accessible to all, especially those with fewer treatment options.

► Support

It is clear that the support for those with ovarian cancer is lacking. We found that the Clinical Nurse Specialist workforce is undervalued and under-resourced which has a knock-on effect on the support available. We found high levels of unmet need including mental health support and support with menopause. There is also a lack of support for those who have finished first line treatment, with those who have a recurrence reporting not having the same level of care as their first line treatment.

To tackle this, we need to see greater long-term investment in support services and the gynaecology Clinical Nurse Specialist workforce.

Pathfinder 2022 shows that we continue to make progress in the diagnosis, treatment, and support for those with ovarian cancer. However, it also shows that there remains an urgent need – and ample opportunity – for this to be faster, further, and fairer in order to achieve the world-class ovarian cancer outcomes that we all want.



Annwen Jones OBE
Chief Executive, Target Ovarian Cancer

Pathfinder methodology

This report is based on the findings of four surveys conducted between January and May 2022.

Women who received a diagnosis of ovarian cancer during or after 2016: Our last Pathfinder study was published in 2016 and this survey aimed to understand the experiences of those diagnosed since then. It was hosted online by Target Ovarian Cancer between February and May 2022 and received 447 responses from across the UK. This was a self-selecting group, who chose to complete the survey, which was promoted to as wide a group as possible.

Public awareness: The awareness survey was carried out by our research partner Survation who interviewed, by phone, 1,002 women across the UK using an adaptation of the Ovarian Cancer Awareness Measure.⁴ This was a weighted representative sample.

UK GPs: 548 GPs were surveyed online between April and May 2022. 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.

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.

UK Clinical Nurse Specialists: 33 Clinical Nurse Specialists responded to an online survey that was promoted between February 2022 and May 2022 via email, social media, and professional organisations. This represents approximately 10 per cent of the gynaecology Clinical Nurse Specialist workforce.

The results from these surveys have provided a mix of quantitative and qualitative data, allowing us a unique opportunity to track trends from previous studies as well as draw a snapshot of the current state of ovarian cancer diagnosis, treatment, and support.

Sadly, we know that one in seven women (14 per cent) die within two months of an ovarian cancer diagnosis, and many will not have had the chance to share their experiences through surveys like this.⁵ The experiences shared in this report must be read with this in mind.

Reflecting the impact of the Covid-19 pandemic

“The worst for me is that throughout the whole time I have had to deal with it on my own from diagnosis, surgery, chemo and parp inhibitor because of covid and no one allowed to accompany me for anything.”

Target Ovarian Cancer surveyed our supporters during in May and June 2020 and found that many were worried about visiting their GP with symptoms, had their treatment disrupted, and had to cope with the mental and emotional impact of being advised to shield.⁶

This latest Pathfinder study covers 2016–2022, shining a spotlight on the experience of ovarian cancer diagnosis and treatment in both the pre-pandemic and the pandemic period. Where possible, we have compared the data for those two periods to identify differences and these are outlined in the report.

“When the cancer returned it was during covid so much of the conversations including being told it was back were over the phone. I was on my own for all hospital visits, treatments and surgery so very stressful.”

Awareness: further to go

“If I had been diagnosed earlier, I might have had a better chance of getting a less serious diagnosis.”

Everyone needs to know the symptoms of ovarian cancer.

With no effective screening, the main route to ovarian cancer being diagnosed is by women visiting their GP with 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.

Target Ovarian Cancer has tracked awareness in the general population of the four key symptoms of ovarian cancer since 2009.

Since our last Pathfinder Study in 2016 we have seen a significant milestone with the first nationwide symptoms awareness campaign in England to feature a symptom of ovarian cancer. In November 2020 NHS England's *help us, help you* campaign launched an abdominal symptoms campaign which featured the symptom of bloating, and in 2021 featured the symptom of abdominal pain.

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

Pathfinder	Persistent bloating (per cent)	Pelvic or abdominal pain (per cent)	Feeling full/loss of appetite (per cent)	Increased urinary urgency/frequency (per cent)
2009	9	24	1	1
2012	17	28	2	1
2016	20	20	3	2
2022	21	32	3	1

“If I had known the signs to look out for maybe my diagnosis would have been a better one.”

There have been welcome improvements in the awareness of abdominal pain and bloating as potential symptoms of ovarian cancer, but we must go further on awareness.

Awareness of feeling full and urinary symptoms have been consistently very low, despite being commonly experienced symptoms. In our survey for those with a diagnosis of ovarian cancer, 38 per cent reported having the symptom of feeling full quickly and 45 per cent reported urinary symptoms. These symptoms must be included in future awareness campaigns so that those who have only those symptoms are not missed.

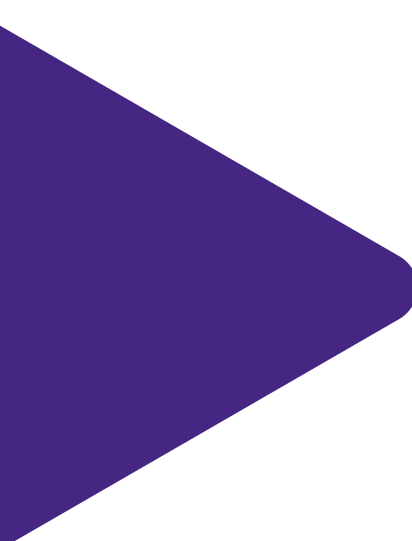
“If more awareness was raised, I’m certain more people will spot it before it’s too late.”

Despite awareness of symptoms tracking upwards since 2009, only three per cent of women surveyed said they were very confident in naming the symptoms. This is likely to mean that even if they spot something is not right, they might not make an appointment or seek advice.

We also found that a worrying 40 per cent of women wrongly believe that cervical screening detects ovarian cancer. This means that women may think that if their cervical screening was clear they are not at risk of developing ovarian cancer.

What needs to happen

- We must urgently go further to raise awareness, with sustained government-funded national awareness campaigns that highlight the symptoms of ovarian cancer in every nation of the UK.
- The information provided at cervical screening appointments must make it clear it does not test or screen for other gynaecological cancers and include the symptoms to look out for.



40%
**of women wrongly
believe that cervical
screening detects
ovarian cancer.**

Diagnosis: a faster pathway is possible

"I knew something was wrong for a long time before I was diagnosed. When I realised what was wrong the GP dismissed my concerns and failed to request the tests I needed. I had to insist I had the CA125 blood test, instead of the usual blood tests which did not show anything abnormal."

Faster diagnosis saves lives – the quicker the diagnosis is received, the more quickly treatment can begin.

The earlier a woman is diagnosed the greater her chance of survival: 93 per cent of women diagnosed at the earliest stage survive for at least five years compared to just 13 per cent of women diagnosed at the most advanced stage.⁷ Shockingly, one in five women diagnosed with ovarian cancer in England are already too ill to receive any treatment and 14 per cent of women in England die within two months of diagnosis.⁸ Our survey respondents will not reflect their experience.

GPs play a vital role in getting the right diagnosis: the outcomes for those diagnosed via an emergency presentation at A&E are much poorer than those diagnosed through visiting their GP.⁹

We must go faster on diagnosis. Our research shows that there are still too many delays in the diagnosis pathway, and that GPs need more training and support.

"I was not aware of the symptoms and so delayed getting a medical appointment, but GP services were very poor in terms of getting an appointment and giving me the results of tests."

Delays in accessing diagnostic tests

Clinical guidelines set out the steps GPs should take for suspected ovarian cancer, including a referral for a CA125 blood test and an ultrasound. In Scotland these tests take place at the same time, but in other parts of the UK the guidance is to wait for the blood test results first. Once these results are received the GP makes the decision on whether to refer on to secondary care.^{10,11}

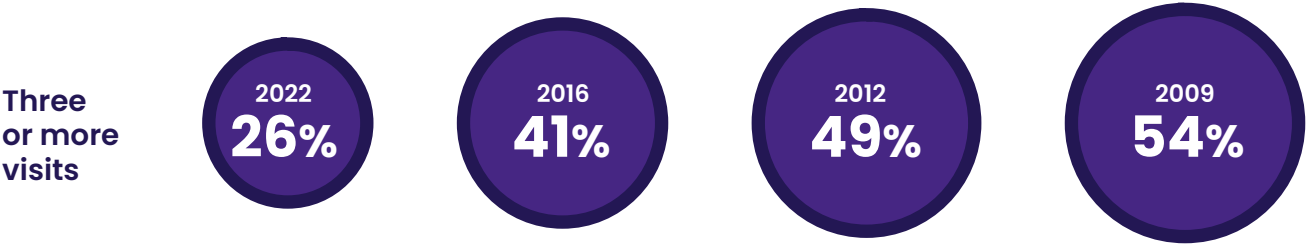
However, 15 per cent of GPs report that they are not aware of these guidelines.

There has been an improvement in those reporting finding out they had ovarian cancer in less than one month from their first visit to the GP, but nearly one third are still waiting over three months for a diagnosis. Over a quarter still report that they are having to make three or more visits to their GP before being referred for tests.

Given the impact this can have on starting treatment, we need to see these timelines reduce. To support better outcomes everyone should receive their diagnosis under three months from their first visit to the GP, and we need to see all those who attend their GP with ovarian cancer symptoms referred for tests within two appointments.

Table 2: How much time passed from your first appointment with the GP to the day you were given your diagnosis?				
	2022	2016	2012	2009
Less than month	30 per cent	27 per cent	21 per cent	23 per cent
More than one month but less than three months	31 per cent	29 per cent	30 per cent	32 per cent
More than three months but less than six months	16 per cent	18 per cent	15 per cent	16 per cent
More than six months but less than a year	7 per cent	12 per cent	17 per cent	14 per cent
More than one year	9 per cent	15 per cent	15 per cent	15 per cent

Figure 1: How many times did you have an appointment with your GP before you were referred for tests?



It is encouraging that almost all GPs now report that they can directly access diagnostic tests, with 99 per cent of GPs reporting that they can order CA125 blood tests directly and 96 per cent can request non-obstetric ultrasound for suspected ovarian cancer. This was something that we called for in our early Pathfinder reports.

Unfortunately, the women and GPs we surveyed reported further delay once these tests were ordered.

Women who have been diagnosed report having to wait before undergoing tests:

- 37 per cent say they waited longer than eight days to have a CA125 blood test.
- 55 per cent say they waited more than eight days to have an ultrasound.

More than one in ten women (11 per cent) reported waiting over 32 days for an ultrasound. This is compounded by delays reported by GPs in how long it takes on average to get the results of an urgent non-obstetric ultrasound for suspected ovarian cancer:

- 40 per cent of GPs report it takes more than 15 days to receive results.
- Eight per cent report waits of over 32 days.

These results demonstrate that there are delays in both undergoing the tests and GPs getting the results, adding up to too long a wait to confirm or rule out ovarian cancer. It is clear that there must be greater investment in diagnostic capacity and the pathway must be shortened.

There is no nationwide way to capture and compare performance in this area. The Faster Diagnosis Standard in England, for example, does not measure the time taken before someone is referred to secondary care with suspected cancer. As suspected ovarian cancer requires these tests before a referral is made, these delays are hidden. We need to see more effective monitoring that includes those tests undertaken in primary care, in order to better reflect the ovarian cancer diagnostic pathway.

GP confidence and knowledge

GPs are the first port of call for someone experiencing symptoms. No GP wants to miss an ovarian cancer diagnosis, but our survey of GPs has found more practical support is needed.

GP awareness of symptoms

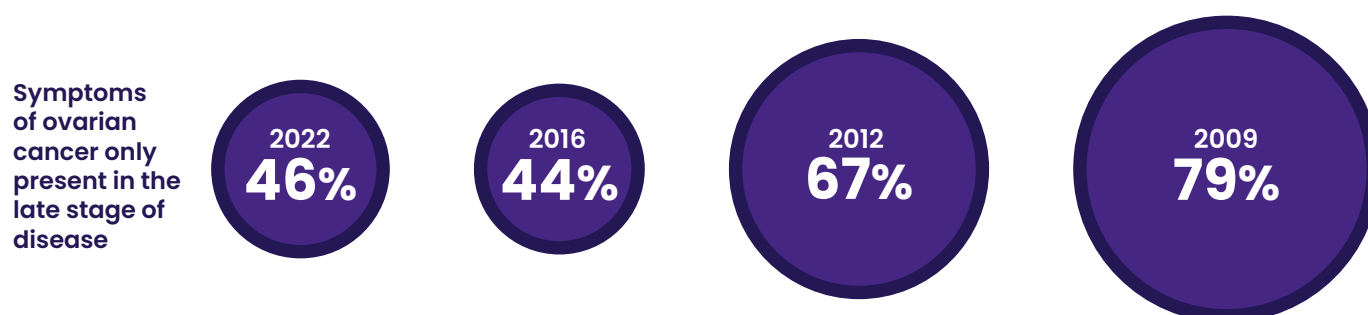
For the first time we surveyed GPs on their knowledge of ovarian cancer symptoms unprompted. We found that GPs had good knowledge of bloating and abdominal pain, but there are gaps in knowledge around other symptoms.

**More than
1 in 10
women (11%) reported
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Figure 2: GP awareness of key ovarian cancer symptoms



Figure 3: Percentage of GPs that agree that ovarian cancer symptoms only present in the late stage of the disease



Despite good knowledge of some of the key symptoms, nearly half of all GPs surveyed agreed that ovarian cancer symptoms only present in the late stage of the disease. This is a concern, as symptoms are often present in those with early-stage disease.¹²

Family history can play a role in assessing the likelihood of ovarian cancer through a variant of the BRCA1 and BRCA2 genes which can be passed on by both parents. However, in our survey only 61 per cent of GPs reported being aware that family history is relevant on both the father's and the mother's side.

Confidence in interpreting tests

GPs use the results of a CA125 blood test and non-obstetric ultrasound to decide whether to make an urgent referral to secondary care with suspected ovarian cancer, so it is important that they feel confident in interpreting results.

However, GPs in our survey told us they need greater support on interpreting tests: only 65 per cent of GPs said that they are confident on interpreting CA125 results and 61 per cent report being confident in interpreting ultrasound results.

61%
**of GPs report being confident in
interpreting ultrasound results.**

GPs report that they find it difficult to know when to re-test following a normal or nominally elevated CA125. Some are unsure how to manage postmenopausal women who are displaying symptoms but have a normal or nominally elevated CA125.

For ultrasound, 28 per cent of GPs said they would like a clear recommendation alongside the descriptive report, and others wanted more clarity on next steps when the report says that the ovaries were not visualised.

More support is urgently needed to ensure GPs are equipped to make the right onward referrals or safety net patients who may need further tests if symptoms persist.

Embracing new innovations

Since our last Pathfinder study, we have seen new innovations in primary care.

The roll out of rapid diagnosis centres and pathways provides a diagnostic route for patients with non-specific but concerning (vague) symptoms who do not fit into existing pathways and may be an opportunity to mitigate repeat GP visits. In our survey, 69 per cent of GPs think that referring all patients with a suspicion of cancer to a diagnostic cancer clinic would possibly or definitely improve the diagnosis of ovarian cancer. As the rapid diagnosis approach is rolled out across the UK it is important that there is a focus on the specific ovarian cancer pathway.

The Covid-19 pandemic saw a dramatic increase in GPs using remote consultations, either by phone, video call or by app. Although this has its advantages, 59 per cent of GPs surveyed think that these can hinder diagnosis of ovarian cancer. Target Ovarian Cancer will be working with our GP network and local partners to ensure primary care teams have the information they need to assess and refer patients with potential ovarian cancer symptoms.

What needs to happen

- Given the time taken to get the results of the CA125 blood test and urgent non-obstetric ultrasound in primary care, there is an urgent need to shorten the ovarian cancer diagnostic pathway with the CA125 blood test and ultrasound undertaken at the same time in line with best practice in Scotland.
- There must be a process established to monitor the speed of an ovarian cancer diagnosis which includes the time taken to access and report on tests in primary care.
- There must be better access to, and support for GPs with accessing and interpreting ultrasound results. To ensure this, there needs to be an increase in the non-obstetric gynaecology sonographer workforce, and sonography should become a regulated profession.
- The NICE guideline on ovarian cancer must be updated to include greater detail on safety netting for GPs, including clearer guidance on when to reinvestigate and greater access to advice and guidance services from secondary care.

Treatment: fairer access needed for all

Everyone with ovarian cancer deserves the best possible treatment, targeted to their needs.

The standard treatment for ovarian cancer is a combination of surgery and chemotherapy, or, in a very few cases, surgery or chemotherapy alone. Since 2016 maintenance treatments in the form of PARP inhibitors have become more available to those diagnosed with advanced high grade serous cancer. This has led to an expansion of genomic treatment meaning more women than ever can access personalised treatments, where they are given a treatment most likely to work on the type of tumour they have.

Surgery is the treatment that offers the best long-term outcomes for ovarian cancer. However, the ovarian cancer audit feasibility pilot found significant differences in access to surgery in England, with four in ten women not having any surgery and one in five women receiving no treatment at all.¹³

The cohort who answered our survey are those that will have survived the first few months after diagnosis so we would expect to see high rates of access to surgery. However, we have seen a worrying trend in women reporting they have not received surgery or been invited to take part in a clinical trial.

Access to surgery

Surgery for ovarian cancer can be complex and can require a significant amount of surgery time and critical care support. This has meant that surgery for ovarian cancer faced significant disruption throughout the Covid-19 pandemic.

Table 3: Have you had surgery as part of your treatment for ovarian cancer?
[Please select all that apply]

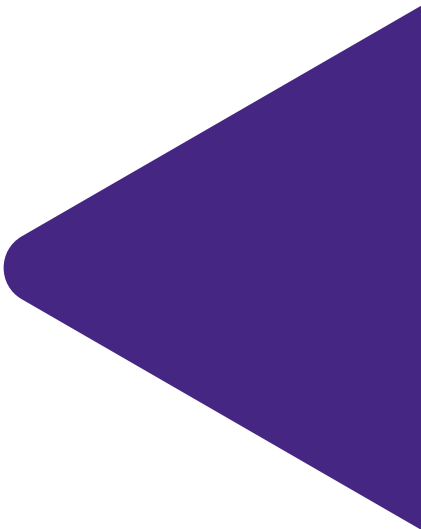
	Diagnosed 2016–2022	Diagnosed 2020–2022 (Pandemic period)	Diagnosed 2016–2019 (Pre-pandemic period)
Yes, as part of the first round of treatment	92 per cent	87 per cent	97 per cent
Yes, when the cancer came back	5 per cent	2 per cent	8 per cent
No, I have not had any surgery	7 per cent	13 per cent	2 per cent

It is clear that the pandemic has had an impact on the availability of surgery. There was a 10 per cent difference reported in access to surgery as part of the first round of treatment during the pandemic period and a six per cent drop in surgery for recurrent ovarian cancer. There was also an 11 per cent increase in those who had no surgery at all in the pandemic period. This aligns with a Target Ovarian Cancer survey undertaken in June 2020 where women with ovarian cancer reported having their surgery postponed and having additional cycles of chemotherapy while waiting for surgery.¹⁴

Surgery must get back on track and go further in ensuring fair access to surgery so that everyone benefits from the best course of treatment for them.

Research has shown that treatment at a specialist multidisciplinary gynaecology cancer centre improves survival by 45 per cent.¹⁵ The data from our surveys did not give us enough detail to assess where surgery and other treatment was undertaken. We need to see better analysis of NHS data to understand where and how surgery is being accessed and the impact that can have on survival.

There was an **11%**
increase in those who
had no surgery at all in
the pandemic period.



Access to genomic testing – a new frontier

There are several genetic faults or mutations linked to ovarian cancer. Of greatest significance is a variation in the BRCA1 or BRCA2 gene which accounts for around 13 per cent of all cases of ovarian cancer.¹⁶ Around half all of those with high grade serous ovarian cancer, the most common type of ovarian cancer, have Homologous Recombination Deficiency (HRD) where the body is unable to repair double strand breaks in DNA. This means that cancer cells have a harder time repairing themselves in people whose tumour tests positive for HRD.

Since our last Pathfinder report in 2016 the genomic testing landscape has radically changed, with ovarian cancer at the forefront of new developments. All those who are diagnosed with high grade serous ovarian cancer are now offered different types of testing:

- BRCA germline testing, usually done by blood test, to see if an inherited or familial BRCA1 or BRCA2 variation is present.
- Somatic testing – where the tumour is tested for the BRCA mutation as well as HRD.

The availability of some PARP inhibitors is dependent on the presence of a BRCA variation or HRD status.¹⁷ This means that genomic testing has a treatment implication for some women with ovarian cancer. However, this must be balanced with the implications of germline testing where the presence of a variation of the BRCA genes means that other family members could have the same mutation and be at risk. This requires access to the right care and support, including genetic counselling.

Of those we surveyed that told us they would have been eligible for testing:

- 86 per cent had BRCA germline testing
- 34 per cent had BRCA somatic testing
- 18 per cent report HRD testing (available across the whole UK from December 2021)

However, 31 per cent of the women who reported receiving genomic testing said that no one in their treatment team told them how the results would affect their treatment options, and 43 per cent said they weren't offered specialist counselling.

Widespread access to genomic testing has improved access to personalised treatment. This means that more women than ever before can find out whether there are implications for their family. However, it is vital that the consenting process for testing is done in such a way that ensures patients are able to make informed decisions. This should include access, where appropriate, to genetic counselling for those undergoing germline testing. There should be an agreed protocol so that access to information is the same no matter who is doing the consenting.

Access to clinical trials

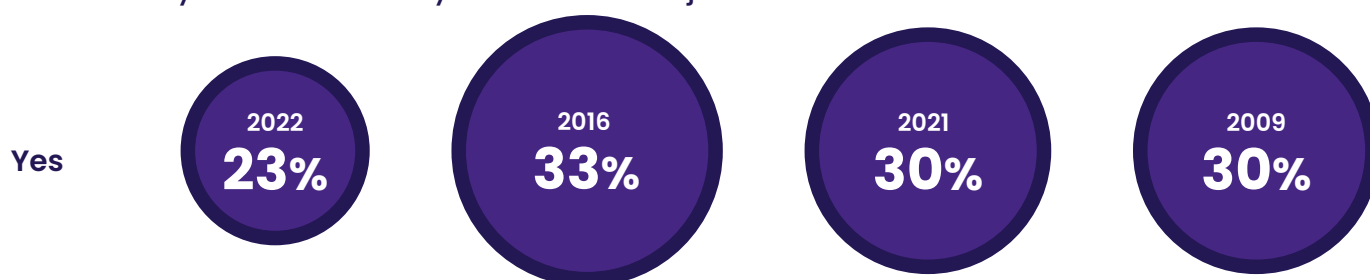
“Nobody asked me and I am too preoccupied to search out a trial myself.”

Clinical trials offer women the opportunity to access experimental cancer drugs, improve understanding of the disease and treatment options, and access the highest quality care. They are also often the only way of accessing new treatment for those who have a rarer ovarian cancer tumour or those who have become resistant to the standard treatment regimen.

“I was asked about research when going into theatre which I thought was inappropriate, stressed and no prior warning to read or digest information.”

Overall, between 2016 and 2022, 23 per cent of survey respondents report being asked if they would like to join a clinical trial. However, this was 31 per cent between 2016 and 2019, and dramatically dropped to just 13 per cent in the 2020 to 2022 pandemic period.

Figure 4: At any stage since diagnosis have you been asked by anyone involved in your treatment if you would like to join a clinical trial?



“I started on a trial in February 2020 but it got cancelled because of covid.”

23% of survey respondents report being asked if they would like to join a clinical trial.

We found a clear desire for greater access to clinical trials, with 60 per cent of those that have not yet taken part in clinical trials telling us they would like to, and 63 per cent who would be prepared to travel to another hospital to take part in a clinical trial. However, women reported not knowing where to access information about trials, and concerns about how and when trials were raised with them.

“I did not know how to find out if I was eligible for any clinical trials. I would have liked to have the opportunity to participate, and I would have liked for suitable trials to be proactively identified and offered to me, as I have no idea how to navigate the system to find out what’s available.”

“I envisage trials are only for people where no other option is available.”

Urgent action needs to be taken to ensure that the decline in opportunities to take part in trials is reversed and information about appropriate trials is shared.

What needs to happen:

- Everyone that would benefit from specialist surgery must be able to access it regardless of age or geographical location.
- There must be capacity in the system to allow for the expected growth of genomic testing, including development of HRD testing across the UK to ensure that results are provided in a timely manner.
- There must be a consistent approach to consenting for genomic testing, with access, where required, to genetic counselling maintained for those having BRCA germline testing.
- Patients must be empowered to ask about clinical trials, with signposting to information on clinical trials embedded into interactions between patients and their clinical team.
- We need to see urgent investment in post pandemic studies that will lead to better treatments.

Support: missing for too many

A diagnosis of ovarian cancer is devastating.

Alongside treatment for ovarian cancer, care and support is crucial to deal with challenges like side effects, the impact of on mental health and reducing feelings of isolation. This should be available at the right time and in the right place, but too often those we surveyed report that this support is not readily accessible.

Getting support right from the start

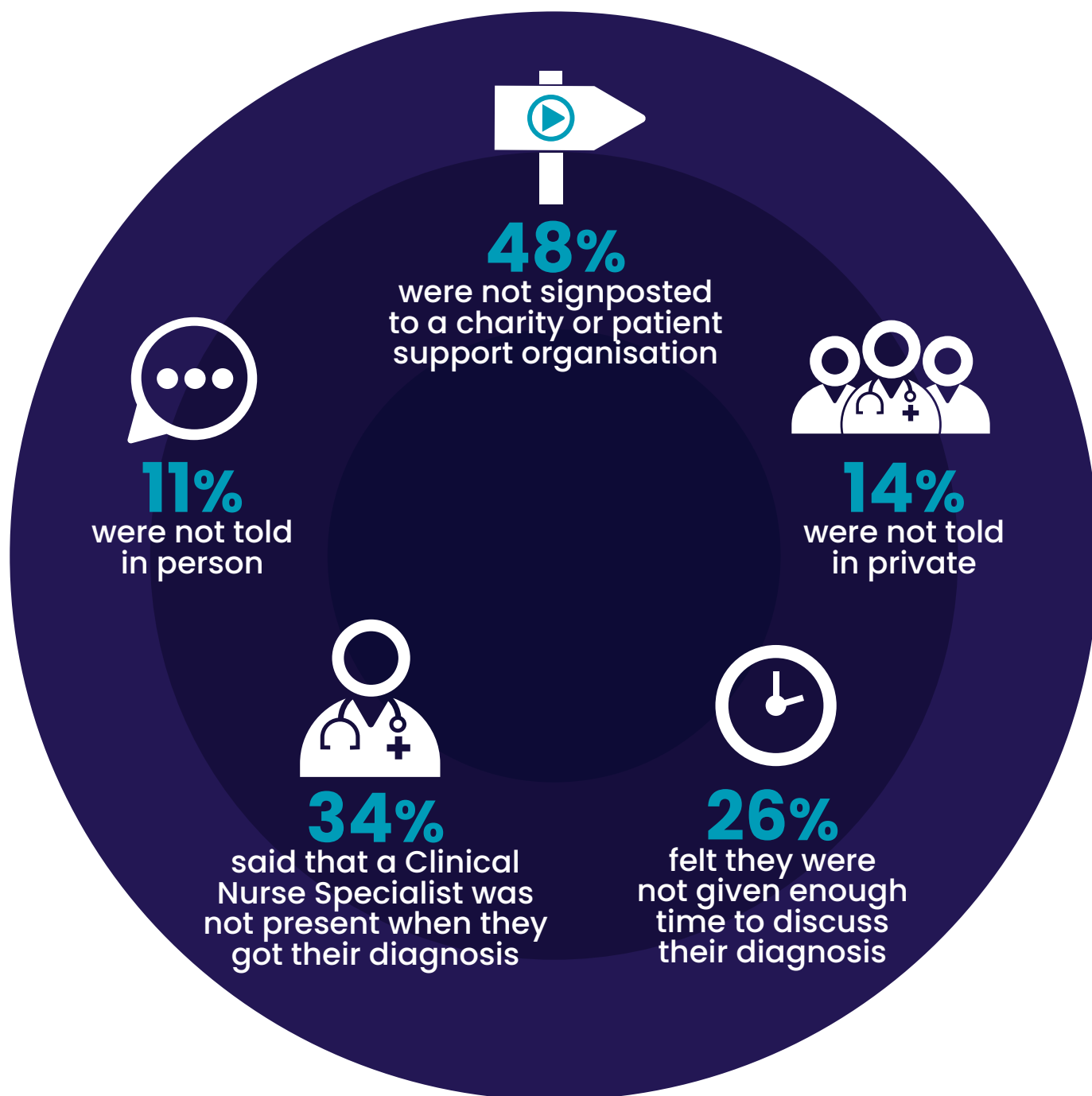
“The only negative part of my treatment is that I was given my initial diagnosis, without my partner, on a general ward after scan, and told it was not curable. No one mentioned that there might be some treatment available. I went home for two weeks thinking I was going to die very soon. After a fortnight, I saw a surgeon who told me about the course of treatment I was to receive.”

It is vital that a diagnosis of ovarian cancer is delivered in the best possible way, personalised to the individual to empower them to make choices about their treatment, care and support. The gold standard for diagnosis should be privately, face to face (either in person or on video call) with enough time for questions and in the presence of a Clinical Nurse Specialist. Everyone should be signposted to an ovarian cancer specific charity or patient support organisation who can provide support.

“I was told of my stage 4 diagnosis behind the curtain on a busy respiratory ward. The rest of the ward heard the conversation.”

However, our survey found significant variation:

Figure 5: experiences of diagnosis



Consideration must be given to delivering a diagnosis of ovarian cancer in the right way, so that everyone has access to the right support, right from the start.

Having a focus on mental health

“This is totally missing from the pathway for cancer, no one acknowledged the fear of the diagnosis.”

Aside from the physical implications of a diagnosis of ovarian cancer, having cancer and the treatment involved can impact on mental wellbeing. In our survey, 60 per cent of those with a diagnosis of ovarian cancer reported it had a negative impact on their mental health.

However, we found that there is a worrying lack of support available. Over half of respondents (54 per cent) report not being asked by anyone involved in their treatment about the impact on their mental health.

“I would have liked to speak with someone but was too frightened of asking, I just hid at home.”

“Post op I saw a psychiatrist who said I didn’t need support. I had a complete breakdown at home post sixth cycle of chemo – horrendous time as I had been running on adrenaline for four months.”

Of those experiencing mental ill health as result of having ovarian cancer, only 30 per cent reported they were referred for support. And for those who were referred, the right support was not always available.

It is clear that there is an urgent need to better embed mental health support in the care and treatment received, from ensuring that it is asked about at every appointment, to having the services available to be referred to.

“I was referred to psychology, but they didn’t think I needed their help.”

“I have had some counselling but sought this out myself via a charity.”

54% were not
asked about the impact
on their mental health.

Taking a holistic approach to support

“I feel I needed support and information but didn’t know how to get it.”

“I think more support with regards to impact on mental health and life overall would be good. You have a devastating diagnosis, quickly into a treatment bubble and then it stops. I think only now am I starting to realise the impact this has had and will continue to have on me and my family.”

In addition to mental health needs, ovarian cancer can affect every area of life. Holistic support, where all the support needs are considered, is vital to maintaining quality of life.

Table 4: In which of the following areas have you needed support since being diagnosed with ovarian cancer?	
Getting life back on track after treatment	66 per cent
Feelings of isolation	75 per cent
Issues relating to body image	75 per cent
Regaining sexual intimacy	77 per cent

Support, when it was available, was often received too late or not offered proactively.

A Holistic Needs Assessment (HNA) is a valuable tool for healthcare teams to establish support needs and concerns and ensure that the right support is given. However, Clinical Nurse Specialists (CNSs) in our survey reported wide variations of when they can carry these out. This is a missed opportunity to assess and address a range of support needs.

“I’m in the process of receiving support and information but very late, it could have been better a year ago. I felt very alone.”

“It’s just so hard to think about asking for help when you feel you have a death sentence”

Table 5: CNSs ability to carry out HNAs: Are you or a member of the CNS team able to complete a holistic needs assessment for women with ovarian cancer?

	All women	Most women	Some women	No women
Around the time of diagnosis and start of treatment for...	30 per cent	42 per cent	12 per cent	15 per cent
Completion of primary treatment for...	6 per cent	27 per cent	24 per cent	42 per cent
Each new episode of disease recurrence for...	3 per cent	21 per cent	33 per cent	42 per cent
The beginning of end of life care for...	6 per cent	15 per cent	27 per cent	52 per cent

Clinical Nurse Specialists also reported in our survey that they are not always able to refer women to the services they need, with just 64 per cent saying they can refer to psychology services, 21 per cent prehabilitation and 39 per cent to psycho-sexual therapy.

“It’s completely affected me. Body image, anxiety, my personality has changed.”

Supporting through menopause

Treatment for ovarian cancer can cause early or surgical menopause because ovaries are removed during surgery. This can have a huge impact on quality of life as well as affecting fertility in younger women. Of those we surveyed, 67 per cent said that they would have liked support dealing with surgical/early onset menopause.

The most common symptoms reported include:

- Hot flushes
- Difficulty sleeping
- Night sweats
- Memory and concentration problems
- Joint stiffness, aches and pains
- Mood changes, such as low mood or anxiety
- A reduced sex drive (libido)
- Vaginal dryness and pain

There is a clear lack of support for those who need support with the menopause, with 62 per cent of those who said they would have liked support saying that menopause was not discussed with them, and 63 per cent telling us that they did not receive any treatment.

This is an under-researched area and more work is needed to understand the scale of the impact of surgical menopause.

“I wish I had had some help with body image and nutrition as I have muddled along by myself, there is a lot of information which often is conflicting.”

What needs to happen

- There should be upscaling of capacity and funding to ensure that the very best support is offered to everyone.
- Diagnosis of ovarian cancer must always be made face to face, in private and with the right support including a Clinical Nurse Specialist present.
- Everybody should be asked about their mental health and emotional wellbeing at every appointment, and services must be in place to support the mental health and wellbeing needs of everyone with an ovarian cancer diagnosis.
- Signposting must be in place to ovarian cancer specific patient support organisations and to reduce isolation and support needs.
- Every patient must have a Holistic Needs Assessment (HNA) or similar in place at diagnosis, at the completion of primary treatment, for each recurrence, and at the beginning of end-of-life treatment.
- There needs to be an agreed protocol for those who experience menopause due to their ovarian cancer treatment with sufficient funding to resource its implementation.

Experiences of recurrent ovarian cancer

“Second time around has been more frightening. I think ladies in this situation need encouragement, reassurance about the treatment and to feel that this is not the end of the line. Even being told ‘you’re doing really well’ means so much.”

Around 70 per cent of those diagnosed with ovarian cancer will experience a recurrence, where the cancer returns after first line treatment.¹⁸

For those who have a recurrence, treatment options have improved since the last Pathfinder study in 2016 with the use of PARP inhibitors as a maintenance treatment for those who have platinum sensitive, high grade serous ovarian cancer.

However, our findings show that those who have a recurrence do not get the same level of support as they did during their first line treatment. Many report not being offered information and support on recurrence at the end of their first line treatment.

Nearly half of those who said they had finished treatment (48 per cent) said that signs and symptoms of recurrent cancer were not discussed with them. In addition, of all our respondents 73 per cent would have liked support coping with fear of recurrence.

73%
**would have liked
support coping with
fear of recurrence.**

Only 33 per cent of Clinical Nurse Specialists report that they are always able to take the time to discuss the signs and symptoms of recurrent ovarian cancer with women before discharge.

Those with a recurrence report that they have a very different experience from first line treatment. When being told the cancer had come back:

- 37 per cent said they had no Clinical Nurse Specialist present
- 51 per cent were not given written information about recurrent ovarian cancer

In addition, 19 per cent reported having no access to a specialist cancer nurse since the cancer returned.

Of the care that they received following their recurrence, 22 per cent said the support they received was not as good as during their first line treatment. In addition, only 45 per cent of Clinical Nurse Specialists reported that cases of recurrent ovarian cancer are always discussed at Multidisciplinary Team meetings.

This is very worrying, as the same standards for diagnosis and support should be applied for a first diagnosis and a recurrence. We need to see action to ensure that those who have a recurrence have access to the best possible treatment and support.

What needs to change

- NICE/SIGN guidelines must be updated to include treatment and support for recurrent ovarian cancer.
- Those with a recurrence should have the same support as first line treatment.
- Stratified follow up pathways should be implemented and properly resourced, with a focus on personalised care and support for those who are concerned about recurrence.

19%
**reported having
no access to a
specialist cancer
nurse since their
cancer returned.**

Experiences of Clinical Nurse Specialists

“The CNS should not be a ‘bit on the side’ in clinic, they should be central to any oncology clinics.”

Clinical Nurse Specialists (CNSs) play a significant role from diagnosis to treatment for anyone diagnosed with ovarian cancer by providing specialist knowledge and emotional support.

From the results of our survey, it is clear that CNSs are under-resourced and overstretched. Over half of the CNSs we surveyed told us there are not enough CNSs employed at their centre or unit to care for all the patients with ovarian cancer.

Patient reported access to a Clinical Nurse Specialist

We found that there is good access to CNSs, with 95 per cent of those with a diagnosis who completed our survey reporting access to a specialist cancer nurse. This has increased from 93 per cent in 2016.

While 85 per cent said that their specialist cancer nurse was always or to some extent available to them, 12 per cent reported that their specialist cancer nurse was not always available to them.

“The needs of ovarian cancer patients have increased in recent years with the advent of PARP inhibitors. This has had an impact on treatment related side-effects and support required from the CNS. Service provision in terms of CNS numbers has not increased to reflect this.”

Challenges to Clinical Nurse Specialist capacity

Our survey of CNSs has highlighted a worrying lack of capacity to attend to the needs of patients:

- 52 per cent say they do not have enough time to attend to the medical needs of patients with ovarian cancer
- 67 per cent say they do not have enough time to attend to the non-medical needs of patients with ovarian cancer

CNSs who completed our survey told us that a number of challenges are affecting their ability to deliver their role: they are seeing patients coming to them more unwell; the widespread use of PARP inhibitors is bringing additional workload without additional resource; and a lack of administration support.

“The workload has increased, and it feels like patients are presenting with more advanced disease. As most of the ovarian cancer patients are followed up at a different hospital it makes supporting patients post treatment more difficult. It feels like we are more stretched.”

Recruitment and retention

As well as impacting patient support, CNSs report that they are not able to take the time to continue their professional development:

- 27 per cent say they are unable to undertake study or Continuous Professional Development appropriate to their role and specialty
- 67 per cent say they cannot take time in their working day to keep up with developments and new treatment modalities

These pressures also appear to be having an impact on CNS' future plans: just 64 per cent plan to remain in their role for the next five years. Gynaecology Clinical Nurse Specialists are the second oldest CNS workforce by tumour type, meaning that we are also likely to see more reach retirement age in the near future.¹⁹

“Clinics are busier than ever which limits time with patients. We are receiving more calls to the service from patients with many different needs, including admin issues as other teams in the hospital are depleted and understaffed. This takes us away from our core CNS functions.”

What needs to happen

- The Clinical Nurse Specialist workforce must be retained, given opportunities for professional development, and investment made into recruiting the next generation of CNSs.
- CNSs must be provided with the necessary administrative support to ensure that they are able to focus on delivering the specialist elements of their role.

Thank 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. The Advisory Panel reviewed our survey – questions and findings. Target Ovarian Cancer has made recommendations based on these findings.

Our patient reviewers: Pauline, Helen, Vicky, Sophie, Lisa, and Lorraine.

Chair: Professor Sudha Sundar – immediate past-President British Gynaecological Cancer Society and Professor of Gynaecological Cancer, Institute of Cancer and Genomic Sciences, University of Birmingham

Dr Shibani Nicum – Associate Professor of Oncology/ Honorary Consultant Medical Oncologist

University College London Cancer Institute

Helen Manderville – Macmillan Gynaecological Oncology Nurse Specialist, Northern Gynaecological Oncology Centre

Lisa Young – Macmillan Lead Gynae Cancer CNS, Wessex Cancer Alliance

Dr Nina Craft – General Practitioner, Woodbrooke Medical Practice, Belfast

Thank you to all the women and health care professionals who responded to our surveys and work with us to make sure their experiences are guiding our work.

This report was written by Rachel Downing, Head of Policy and Campaigns at Target Ovarian Cancer.



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About Target Ovarian Cancer

At Target Ovarian Cancer, we target what's important to stop ovarian cancer devastating lives.

We give trusted information, to help people ask questions and make decisions that are right for them. We connect people with shared experiences, and we support families every step of the way.

We stand together as a powerful community for everyone facing ovarian cancer across the UK, sharing stories and raising voices, to make sure that ovarian cancer becomes a health priority.

We know that early diagnosis saves lives, so we work closely with GPs who are at the heart of this, to help them diagnose ovarian cancer faster and earlier – giving everyone the best chance of living.

And our investment in research to find new, better and more targeted treatments means that everyone can live with hope for their future.

We're fighting for a world where everyone with ovarian cancer lives, and we're targeting what's important – symptoms awareness, early diagnosis, better treatments and support for all.



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