



Pathfinder
Northern Ireland:
**Faster, further,
and fairer**



Contents

▶ Foreword	3
▶ Key findings	5
▶ Awareness: further to go	6
▶ Diagnosis: a faster diagnostic pathway is possible	7
▶ Treatment: fairer access for all	10
▶ Support: missing for too many	12
▶ Recurrent ovarian cancer	14
▶ References	15



For the methodology used in this research and references please visit: targetovariancancer.org.uk/pathfinder

Foreword

Ovarian cancer can be devastating and survival rates in Northern Ireland are among the worst in Europe. Over 200 women are diagnosed with ovarian cancer in Northern Ireland each year and over half of women are diagnosed at a late stage (stage III or IV) when the disease is more difficult to treat.¹

Target Ovarian Cancer was founded in 2008 to change this. One of the charity's key early priorities was to carry out the Pathfinder study to identify what is working and, critically, what needs to change to drive forward urgently needed improvements in survival and support. We carry out the Pathfinder study in Northern Ireland as well as across the UK.

Our Pathfinder Northern Ireland research is made up of three surveys:

- ▶ Awareness of symptoms in women in the general public in Northern Ireland
- ▶ GPs in Northern Ireland
- ▶ Women in Northern Ireland who were diagnosed with ovarian cancer between 2016 and 2022.

31 per cent of women in Northern Ireland diagnosed with ovarian cancer will not survive for one year.² This means that many will not have had the chance to share their experiences through surveys like this. The experiences shared in this report must be read with this in mind.

We first carried out the Pathfinder study in Northern Ireland in 2016 and have seen some welcome areas of progress since then including:

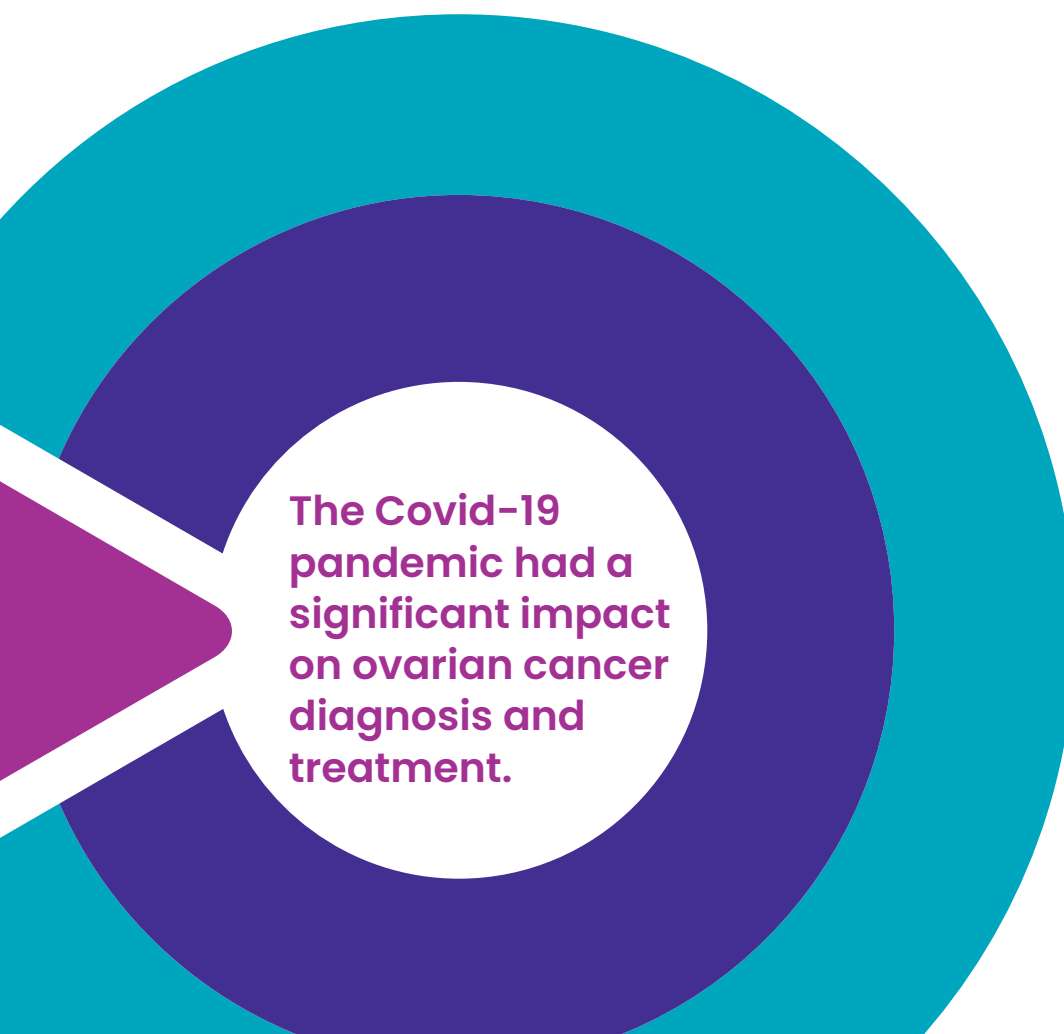
- ▶ Exciting progress in ovarian cancer treatment with the introduction of PARP inhibitors.

Over 200 women are diagnosed with ovarian cancer in Northern Ireland each year.

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 March 2022, a ten-year cancer strategy for Northern Ireland was launched with welcome commitments to deliver regular 'Be Cancer Aware' campaigns and plans to develop new diagnostic pathways and services.

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 health and care staff in Northern Ireland 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.



The Covid-19 pandemic had a significant impact on ovarian cancer diagnosis and treatment.

Key findings

Awareness

Awareness of ovarian cancer symptoms in the general population has shown some improvement since we first started measuring this in Northern Ireland in 2016. However, progress has been slow, and we have seen little improvement in the knowledge of feeling full and urinary symptoms, and 46 per cent of women in Northern Ireland wrongly believe that cervical screening detects ovarian cancer.

Diagnosis

The faster ovarian cancer is diagnosed, the greater the chance of receiving treatment and the greater the chance of survival. We surveyed GPs' knowledge of symptoms 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, we also found delays in both access to diagnostic tests and to 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 the rollout of genomic testing moves at pace, it is vital that the consent process empowers patients to make the best choice for them, which is not always the case. We found little progress in increasing access to clinical trials.

Support

It is clear that support for those with ovarian cancer is lacking. We found high levels of unmet need including mental health support and holistic needs.

Pathfinder Northern Ireland 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 for women in Northern Ireland we all want.

Awareness: further to go

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 among women in the general population of the four key symptoms of ovarian cancer in Northern Ireland since 2016 (Table 1).

Despite awareness of some symptoms tracking upwards since 2016, only four 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 with their GP or seek advice.

We also found that a worrying 46 per cent of women in Northern Ireland 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.

Table 1: Symptoms awareness in the general population in Northern Ireland

Symptom	2016	2022
Bloating	25%	33%
Abdominal pain	27%	32%
Feeling full	4%	2%
Urinary urgency	4%	0%

Recommendations

- ▶ There is an urgent need for government funded awareness campaigns across Northern Ireland to highlight the symptoms of ovarian cancer and encourage women with concerns to visit their GP.
- ▶ The information provided at cervical screening appointments must make it clear it does not test or screen for other gynaecological cancers and must include the symptoms of ovarian cancer.

Diagnosis:

a faster diagnostic pathway is possible

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: 90 per cent of women diagnosed at the earliest stage (stage I or II) survive for at least five years compared to just 14 per cent of women diagnosed at the most advanced stage (stage III and IV).³ Currently in Northern Ireland, over half of women are diagnosed at a late stage.⁴

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.

Delays in getting tested

We surveyed women with ovarian cancer in Northern Ireland about their experience of diagnosis, and many reported delays:

- ▶ 19 per cent reported visiting their GP three or more times before being referred for tests.
- ▶ 30 per cent of those we surveyed reported waiting more than three months from their first appointment with their GP to receiving their diagnosis.

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:

- ▶ 42 per cent say they waited eight days or more to have a CA125 blood test.
- ▶ 56 per cent waited eight days or more to have an ultrasound.

GPs in Northern Ireland we surveyed reported that 90 per cent of urgent CA125 blood test results are received within seven days. However, GPs report longer waits for the results of an urgent non-obstetric ultrasound for suspected ovarian cancer:

- ▶ 58 per cent of GPs report it takes 15 days or more to receive results.
- ▶ This includes 23 per cent of GPs who report waits of 32 days or more.

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.

GP confidence and knowledge

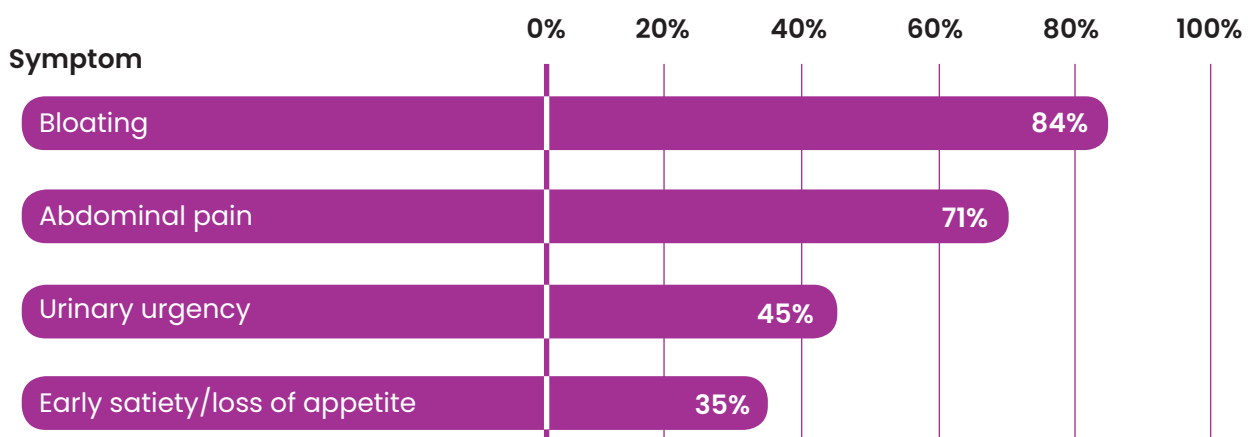
GPs are the first port of call for someone experiencing symptoms. No GP wants to miss an ovarian cancer diagnosis, but our survey of GPs has found more practical support is needed.

We surveyed GPs in Northern Ireland on their knowledge of key ovarian cancer symptoms (Figure 1).

We found that GPs had good knowledge of bloating and abdominal pain, but there are gaps in knowledge around other symptoms.

GPs would also benefit from education on key facts about ovarian cancer, with 39 per cent believing incorrectly that symptoms only present in the late stage of the disease.

Figure 1: GP awareness of key ovarian cancer symptoms



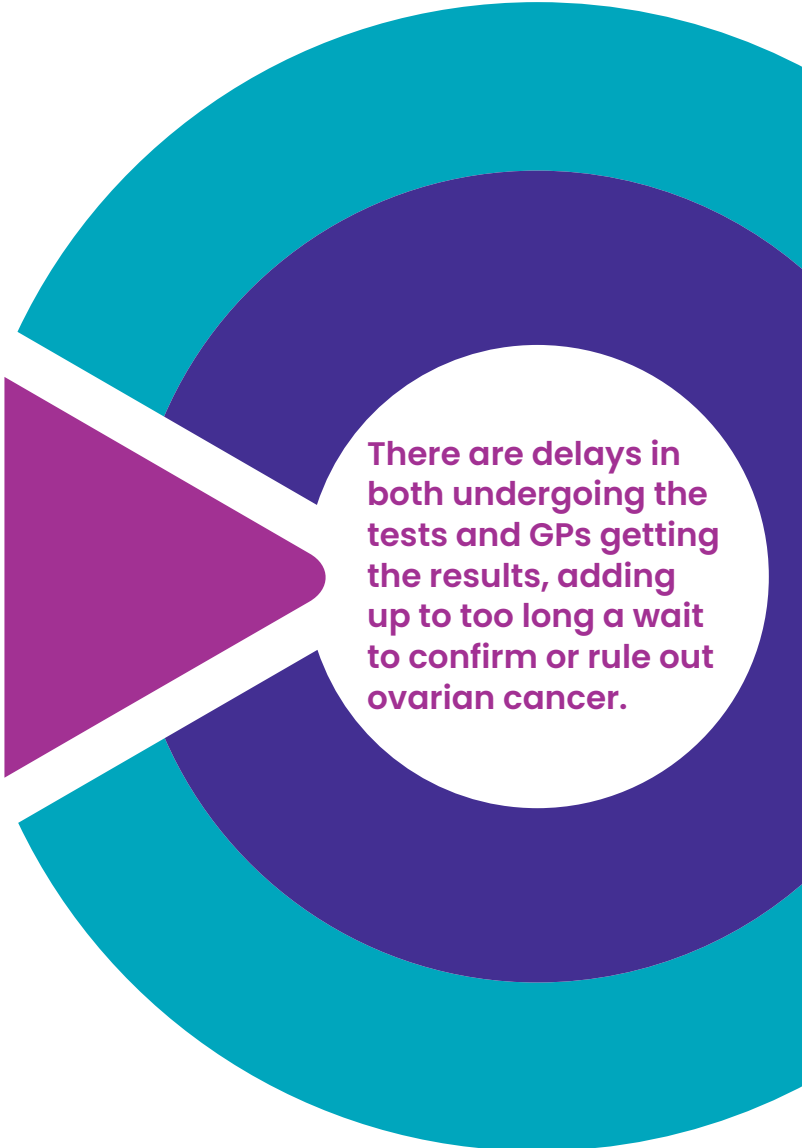
GPs also report needing more support with interpreting test results.

- ▶ 77 per cent of GPs are confident in interpreting CA125 test results.
- ▶ 71 per cent of GPs are 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, 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.

New ways of working are also proving challenging with 55 per cent of GPs in Northern Ireland telling us they think remote consultations can hinder ovarian cancer diagnosis. There is a clear need for support and best practice for GPs.



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Recommendations

- ▶ **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 in Northern Ireland with the CA125 blood test and ultrasound undertaken at the same time.**
- ▶ **There must be better support for GPs across Northern Ireland to interpret and act on CA125 blood test and ultrasound results.**

Treatment: fairer access for all

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

We have seen major steps forward in treatment since 2016 with the introduction of PARP inhibitors – the biggest improvement in treatment options in almost 30 years. There remains more work to be done in improving access to clinical trials and treatment.

Access to clinical trials

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 treatments for those who have a rarer type of ovarian cancer or those who have become resistant to the standard treatment regimen.

There has been no improvement in access to clinical trials since our last Pathfinder research in 2016 (Figure 2). This is despite a clear desire to take part in clinical trials with 70 per cent of respondents who had not taken part in a clinical trial wanting to do so and 73 per cent prepared to travel to a different hospital to take part in a trial.

The lack of growth in clinical trials may be due to the lack of availability due to the Covid-19 pandemic. Urgent action is needed to identify the barriers to clinical trial participation and ensure that information about appropriate trials is shared proactively with patients.

Genomic testing

Since our last Pathfinder research in 2016, the genomic testing landscape has radically changed, with ovarian cancer at the forefront of new developments.

Figure 2: At any stage since diagnosis have you been asked by anyone involved in your treatment if you would like to join a clinical trial?

- ▶ 2022 Yes: 11 per cent
- ▶ 2016 Yes: 11 per cent

The availability of some PARP inhibitors is dependent on the presence of a BRCA variation or HRD status.⁵ This means that genomic testing has a treatment implication for some women with ovarian cancer. The presence of a BRCA germline variant also has implications for family members as they may also have the gene, so women need the right genetic counselling support when undergoing BRCA germline testing.

Of those we surveyed:

- ▶ 67 per cent had received BRCA germline testing.
- ▶ 22 per cent had received BRCA somatic testing.
- ▶ 15 per cent had received HRD testing (available across the whole UK from December 2021).

However, 52 per cent said they weren't offered specialist counselling to help them decide if they wanted to be tested for a germline mutation.

Access to surgery

Research has shown that treatment at a specialist multidisciplinary gynaecology cancer centre improves survival rates by 45 per cent.⁶ The data from our surveys did not give us enough detail to assess where surgery and other treatment was undertaken, or what proportion of women in Northern Ireland receive surgery. We need to see better analysis of data to understand where and how surgery is being accessed and the impact that can have on survival.

Recommendations

- ▶ 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.
- ▶ There must be a consistent approach to consenting for genomic testing, with access, where required, to genetic counselling for those having BRCA germline testing.
- ▶ Everyone that would benefit from specialist surgery must be able to access it no matter where they live in Northern Ireland.

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 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

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 is that it should be delivered 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.



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However, our survey found significant variation in women's experience of diagnosis:

- ▶ 26 per cent were not told in private.
- ▶ 33 per cent were not signposted to a charity or patient support organisation.
- ▶ 25 per cent felt they were not given enough time to discuss their diagnosis.
- ▶ 28 per cent said that a Clinical Nurse Specialist or Macmillan nurse was not present when they got their diagnosis. .

96 per cent of those surveyed reported they had access to a specialist cancer nurse, but 19 per cent said that their CNS was not always available when they wanted to speak to them.

Mental health

Aside from the physical implications of a diagnosis of ovarian cancer, having cancer and the treatment involved can impact on mental wellbeing:

- ▶ 52 per cent of those surveyed said having ovarian cancer had a negative impact on their mental health.
- ▶ 48 per cent were never asked about the impact of their treatment on their mental health.
- ▶ 23 per cent of those experiencing mental ill health as a result of having ovarian cancer reported they were not referred for support.

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

Taking a holistic approach to support

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 2).

Table 2: In which of the following areas have you needed support since being diagnosed with ovarian cancer?

Getting life back on track after treatment	62%
Feelings of isolation	71%
Coming to terms with my diagnosis	62%

Clinical Nurse Specialists are key to the provision of support. Target Ovarian Cancer surveyed CNSs across the UK and found that they are overstretched with not enough time to provide for both medical and support needs of their patients. Tackling the support gap requires urgent investment in the CNS workforce.⁷

Recommendations

- ▶ **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.**
- ▶ **The Clinical Nurse Specialist workforce are vital to providing support so must be retained, given opportunities for professional development and investment made into recruiting the next generation of CNSs.**

Recurrent ovarian cancer

Around 70 per cent of those diagnosed with ovarian cancer will experience a recurrence, where the cancer returns after first line treatment.⁸

It is important that those who have finished first line treatment are equipped with the knowledge and support around recurrence, but our survey found that this is often not provided:

- ▶ 72 per cent reported needing support coping with fear of recurrence.
- ▶ 50 per cent said signs and symptoms of recurrent ovarian cancer were not discussed with them at the end of their cancer treatment.

Recommendation

- ▶ **Those with a recurrence should have the same support as first line treatment and all those who have had first line treatment should have signs of recurrence discussed with them.**

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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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