



Pathfinder Northern Ireland

**Transforming futures
for women with
ovarian cancer**

Pathfinder Northern Ireland at a glance

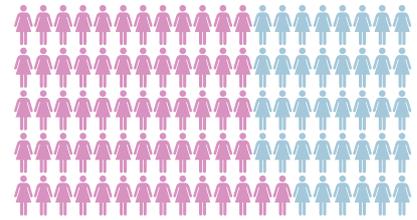


25%

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

38%

of women incorrectly believe cervical screening also detects ovarian cancer



40%

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

32%

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



73%

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



60%

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



86%

of women with ovarian cancer experience mental ill health

Pathfinder Northern Ireland at a glance	2
Introduction	4
Awareness of symptoms	6
Diagnosis	7
Genetics	8
Starting treatment	9
Clinical trials	10
Support	11
Mental wellbeing and body image	11
Recurrence	11
Conclusions	12
Thank you	16
The Pathfinder Advisory Panel	16
Methodology	17
References	19

Target Ovarian Cancer works to improve early diagnosis, fund life saving research and provide much needed support to women with 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.

In Northern Ireland we:

- hold Being Together support days for women with ovarian cancer.
- distribute our guides and information to cancer centres across Northern Ireland.
- promote our free GP toolkit to improve early diagnosis.

Nearly 200 women are diagnosed with ovarian cancer in Northern Ireland every year.¹ In recent years there has been an increasing effort to raise awareness of the disease:

- In 2013 Members of the Legislative Assembly called on the then Minister of Health, Social Services and Public Safety to ‘consider an awareness campaign on this issue’.²
- In 2014 Una Crudden, who had received a terminal diagnosis of ovarian cancer, worked with the Public Health Agency and charities, including Target Ovarian Cancer, to run an ovarian cancer awareness campaign which saw leaflets and posters distributed across Northern Ireland highlighting the key symptoms for women to look out for.
- Target Ovarian Cancer’s leaflet with information on the symptoms of ovarian cancer has been available on the Public Health Agency’s Be Cancer Aware website since the awareness programme’s launch in 2015.

However, while survival rates have improved in recent years, they still lag behind those for other cancers and over 100 women die of the disease in Northern Ireland every year.³

It is clear more needs to be done and this is therefore a critical time to be publishing the first Pathfinder Northern Ireland, looking at women’s awareness of ovarian cancer, their experience of diagnosis and treatment and GP knowledge.

Pathfinder Northern Ireland is based on three different surveys:

- Women in the general population
- Women with ovarian cancer
- Practising GPs

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.

While recognising the work that has been done already to improve the diagnosis and treatment of ovarian cancer, Pathfinder Northern Ireland sets out what needs to happen next to transform outcomes for women living with ovarian cancer in Northern Ireland today, and those diagnosed tomorrow.

The top three actions identified by Pathfinder Northern Ireland are:

- A Be Cancer Aware campaign that includes the symptoms of ovarian cancer so women know the symptoms to look out for and the importance of going to the GP.
- NHS Northern Ireland to ensure all women with ovarian cancer are given information on clinical trials and how to access them.
- NHS Northern Ireland to ensure all women with ovarian cancer are aware of where to go for support, including counselling.



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 as set out in National Institute for Health and Care Excellence (NICE) guidelines 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 ⁴

Women in the general population were asked to say which symptoms they think might be linked to ovarian cancer.

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

Persistent bloating (per cent)	25
Pelvic or abdominal pain (per cent)	27
Feeling full/loss of appetite (per cent)	4
Increased urinary urgency/frequency (per cent)	4

There is also widespread confusion with cervical cancer, with 38 per cent of women in Northern Ireland incorrectly believing that cervical screening also detects ovarian cancer.

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 in Northern Ireland know the warning signs.

Just 36 per cent of women with ovarian cancer in Northern Ireland are diagnosed with Stage I disease (where survival is highest).⁵

NICE 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 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).

In the past many GPs have held mistaken beliefs around the diagnosis of ovarian cancer and Table 2 shows that these persist today, with many GPs in Northern Ireland wrongly believing that ovarian cancer cannot be picked up early or does not have recognisable symptoms. This is despite clear clinical guidelines to the contrary.

Table 2. GP beliefs regarding presentation of symptoms of ovarian cancer

GPs saying symptoms only present in the later stages of the disease (per cent)	40
GPs saying ovarian cancer is a silent killer (per cent)	87

32 per cent of women subsequently diagnosed with ovarian cancer visited their GP three times or more before being referred for diagnostic tests and 52 per cent of women were initially referred for tests for something other than ovarian cancer. Table 3 shows that 74 per cent of women are waiting one month or more for a diagnosis after their first visit to the GP.

Table 3. Time taken from first visiting GP to receiving diagnosis

Less than one month (per cent)	22
One to three months (per cent)	33
Over three months (per cent)	41

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

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.⁶ 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.⁷ 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 that they pass it on to their child.

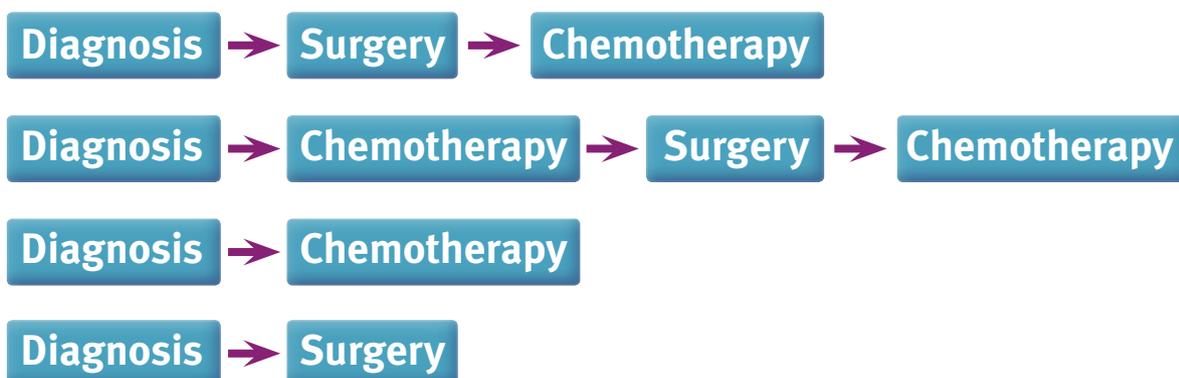
Despite this, there is low awareness of the significance of genetics in relation to ovarian cancer. Among women in the general population in Northern Ireland, only 23 per cent think genetics might be a factor in developing ovarian cancer while 37 per cent of women with ovarian cancer in Northern Ireland are aware 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 47 per cent saying this mattered.



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.⁸ Tables 4 and 5 show that women in Northern Ireland are receiving excellent care and attention from medical staff when it comes to explaining their diagnosis and treatment, but also show that a significant number of women are not receiving written information in addition to a verbal explanation.

Given the volume of information patients are often faced with having to take in at a challenging time, written information is important in providing them with something they can refer back to.

Table 4. Women reporting their diagnosis and treatment was explained to them in a way they could understand

Diagnosis explained in a way women could understand (per cent)	93
Surgery explained in a way women could understand (per cent)	96
Chemotherapy explained in a way women could understand (per cent)	100

Table 5. Women reporting they were provided with written information at diagnosis and during treatment

Written information at point of diagnosis (per cent)	73
Written information before surgery (per cent)	68
Written information before chemotherapy (per cent)	100



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.⁹

In Northern Ireland, 11 per cent of women with ovarian cancer had been asked if they would like to take part in a clinical trial and 4 per cent had joined a trial. Findings also showed that the majority of women (60 per cent) were prepared to travel to another hospital in order to take part in a clinical trial.



Support

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. 100 per cent of women with ovarian cancer in Northern Ireland reported having access to a CNS.

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

86 per cent of women with ovarian cancer living in Northern Ireland report having experienced mental ill health (including depression, anxiety, stress, low mood and mood swings) since being diagnosed with ovarian cancer. In contrast, just 59 per cent of women said anyone involved in their treatment had discussed their mental wellbeing with them.

Body image and sexuality

Many women struggle with their body image post treatment and with regaining sexual intimacy. 82 per cent of women with ovarian cancer in Northern Ireland said they had experienced a loss of self esteem, 53 per cent of women reported difficulties with intimacy and 78 per cent reported a lower sex drive.

Recurrence

Many women are not having possible symptoms of recurrent ovarian cancer discussed with them after completing treatment. 44 per cent of women with ovarian cancer living in Northern Ireland said no one talked them through the symptoms of recurrent ovarian cancer. At the same time, 66 per cent of women said they needed support coping with the fear of recurrence.

Conclusions

The findings in the preceding pages show what is working when it comes to diagnosing and treating ovarian cancer in Northern Ireland, but they also show where more remains to be done, including in the following areas:

Awareness

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.

Be Cancer Aware is aimed at improving cancer survival through raising awareness of the symptoms of cancer and encouraging people to visit their GP sooner. To date the programme has featured campaigns on lung and breast cancer, but aside from information on the Be Cancer Aware website, there has been no wider work around ovarian cancer.

Action

A Be Cancer Aware campaign that includes the symptoms of ovarian cancer so women know the symptoms to look out for and the importance of going to the GP.



Diagnosis

Women in Northern Ireland are making multiple visits to their GP before being referred for diagnostic tests.

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.



Action

Target Ovarian Cancer to distribute their free guide on genetic testing to Northern Ireland cancer centres.



Treatment

Women's feedback on the way their diagnosis and treatment is explained to them is extremely promising, showing that the majority of women are having their treatment explained to them in a clear and accessible manner.

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 it.

Action

NHS Northern Ireland to ensure all women are 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 are discussed with only a minority of patients. This might be related to clinicians' concerns about the suitability of trials, the distances involved or the availability of trials at that point in time.

However, many women are prepared to travel to access the latest trials and it is important that 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 a person helps them understand the situation and be better informed about the options available to them.

Action

NHS Northern Ireland 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 coping with fears of recurrence

Over half of women say they need support coping with the fear of the disease returning. The first step in meeting this is ensuring that every woman is told the symptoms to look out for and what to do if she is worried that the ovarian cancer may have returned.

Action

NHS Northern Ireland to ensure all women with ovarian cancer have the symptoms of recurrent disease discussed with them following treatment.



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 Northern Ireland 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

NHS Northern Ireland to ensure all women with ovarian cancer are aware of where to go for support, including counselling.



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.





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; 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 (Northern Ireland)
- Sarah Burton, Gynaecological Oncology Clinical Nurse Specialist at the Velindre Cancer Centre, Cardiff
- Dr Alexandra Cran-McGreehin, relative advocate (Scotland)
- 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
- Christine Mitchell, patient advocate (Scotland)
- Dr Andy Nordin, President of the British Gynaecological Cancer Society and Consultant Gynaecologist at The Queen Elizabeth The Queen Mother Hospital, East Kent
- Natalie Percival, President of the National Forum of Gynaecological Oncology Nurses and Advanced Nurse Practitioner at the Royal Marsden Hospital, London
- Paul Shagouri, relative advocate (England)
- Professor Debbie Sharp OBE, Professor of Primary Care at Bristol University and member of Target Ovarian Cancer's GP Advisory Board

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

Pathfinder Northern Ireland is based on three different surveys:

- Women in the general population
- Practising GPs
- Women with ovarian cancer

Awareness among women in the general population

The Ovarian Cancer Awareness Measure, a validated tool, was used to measure awareness of ovarian cancer among women in the general population.¹⁰

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 100 women living in Northern Ireland took part in the survey and 1,343 women across the UK as a whole.

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 practising GPs

A survey of practising 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 practising 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. A total of 30 GPs practising in Northern Ireland took part in the survey and 504 GPs across the UK as a whole.

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 currently living in the UK (approximately 500 in Northern Ireland and 16,000 across the UK as a whole).¹¹

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 30 women with ovarian cancer living in Northern Ireland took part in the survey and 396 women across the UK as a whole.



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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.



-  2 Angel Gate, London, EC1V 2PT
-  020 7923 5470
-  info@targetovariancancer.org.uk
-  targetovariancancer.org.uk
-  facebook.com/TargetOvarianCancer
-  [@TargetOvarian](https://twitter.com/TargetOvarian)

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