



## **Target Ovarian Cancer response to NHS Long Term Plan call for evidence**

**December 2024**

### **Q1. What does your organisation want to see included in the 10-Year Health Plan and why?**

Each year over 6,000 women are diagnosed with ovarian cancer in England and, tragically but avoidably one in seven women die within two months of diagnosis. Target Ovarian Cancer are working to ensure women are equipped with information, can access the tests they need and the treatment they deserve no matter where they live.

#### **Long term government funded symptom awareness campaigns**

Within in the new 10 Year Health Plan, we want to see a commitment to a funded awareness campaign that features the symptoms of ovarian cancer. Ovarian cancer symptoms commonly present as abdominal symptoms including bloating, abdominal pain, urinary symptoms and loss of appetite, it is vital that women know that these common symptoms could be caused by ovarian cancer and feel empowered to seek help.

Target Ovarian Cancer research found that just 1 in 5 women are able to recognise the symptom of bloating and 40 per cent of women in the UK wrongly believe that cervical screening detects ovarian cancer. With no viable screening programme, it is vital that everyone is aware of the symptoms if we're to see a reduction in the time it takes to get a diagnosis and ensure that women with early-stage disease are identified.

#### **Investment in tools and pathways that promote earlier diagnosis**

The earlier a woman is diagnosed with ovarian cancer the greater her chance of survival. GP and public awareness are key to early diagnosis. Target Ovarian Cancer found that 26 per cent of women visit their GP three times or more before being referred for diagnostic tests and there is significant regional variation when it comes to early diagnosis. Every cancer is different, with each having different pathways to diagnosis, within the 10-year plan there must be a commitment to improve access to diagnostic tests in primary care, ensuring appropriate education and support is in place for GPs to accurately diagnose early-stage disease. For ovarian cancer a shorter diagnostic pathway would be transformative in achieving an earlier and faster diagnosis.

## **Equitable access to high quality treatment**

Everyone with ovarian cancer deserves the best possible treatment, targeted to their needs. Access to the right treatment is vital to improving a woman's chance of survival, and surgery is the treatment that offers the best long-term prognosis. Access to treatment should not be determined by age or where you live, and yet we know there is significant variation across England when it comes to access to treatment for ovarian cancer, with four in ten women with ovarian cancer across England not receiving surgery as part of their treatment and one in five women receiving no treatment at all. Target Ovarian Cancer would like to see a commitment in the 10 Year Health Plan to address regional variation in access to treatment, ensuring women diagnosed with ovarian cancer are able to access the very best surgery and other treatment no matter where they live.

## **Support and wellbeing**

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 all too often those with ovarian cancer report that this is not the case. Over half report never being asked about their mental health during treatment. Of those experiencing mental ill health as result of having ovarian cancer, only 30 per cent reported they were referred for support. There is an urgent need for the 10 Year Health Plan 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.

## **Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?**

Whilst many parts of cancer care are best undertaken in hospital, access to diagnostics and support can be carried out in the community. GPs play a vital role in getting the right diagnosis and we know the outcomes for those diagnosed via an emergency presentation at A&E are much poorer than those diagnosed through a GP referral. To ensure more people are to receive a timely diagnosis, the 10 Year Health Plan must set out steps to improve access to diagnostic tests and education for GPs.

## **Challenges**

### **Preventing diagnosis in A&E**

Those diagnosed with ovarian cancer through an emergency presentation will have poorer outcomes with just 21 per cent of women with ovarian cancer diagnosed through emergency presentation surviving for five years and currently four in ten women with ovarian cancer have an emergency presentation 28 days before their diagnosis.

**Access to timely and high-quality diagnostic tests** Once a woman has been referred by her GP for tests, it is vital that either ovarian cancer is diagnosed or ruled out as soon as possible. However, we know there can still be unnecessary delays in diagnosis, with GPs facing challenges with both accessing tests and the time taken to receive results. Currently to get a diagnosis, women need their GP to refer them for a CA125 blood test and if that is raised then an ultrasound can be ordered. The CA125 blood test is not always an accurate marker for early-stage disease meaning that it may not be picked up until the disease has progressed

### **Poor quality data on primary care diagnostic tests**

There is currently no data routinely collected on the number of CA125s, and ultrasounds for suspected ovarian cancer ordered in primary care, the main route to diagnosis for ovarian cancer and the outcomes of these tests. Without this data developing interventions to improve diagnosis is challenging.

### **Enablers**

#### **GP workforce capacity and training**

GPs have faced significant pressure in recent years, with the British Medical Association finding that in September 2024 there were the equivalent of 1,399 fewer fully qualified full-time GPs than there were in September 2015. To address the challenges around GP capacity and to ensure we can meet the NHS England ambition of diagnosing 75 per cent of cancer at stage I or II we need to see investment in the GP workforce, ensuring GPs have access to appropriate support and training. Retaining and educating GPs is crucial, they play a key role in diagnosing ovarian cancer.

Target Ovarian Cancer research has found that there are delays in both undergoing diagnostic tests and GPs getting the results. In order to have a more accurate picture of the diagnostic pathway, address the challenges and enable more care to move from hospitals to community we need to see more effective monitoring and evaluation of data between primary and secondary care, including data on tests undertaken in primary care.

#### **Shorter diagnostic pathway and symptom triggered referral**

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. This would improve waiting times and will help achieve an earlier diagnosis.

[Recent research](#) has proved that symptom triggered testing, prompted by symptoms such as pain, abdominal bloating/swelling, and feeling full soon after starting to eat, can pick up early-stage aggressive ovarian cancer in 1 in 4 of those affected and that complete surgical removal of the cancerous tissue is possible even in more advanced disease, providing that women with suspicious symptoms are expedited

for investigation and treatment. This highlights the need for GPs to act quickly on ovarian cancer symptoms.

### **High quality ultrasound**

Ovarian cancer can [be detected in 96 per cent of post – menopausal women if the IOTA – ANDEX model](#) was adopted to replace the current standard of care test called risk of malignancy (RMI1) test in the UK which identifies 83% of ovarian cancers. Vital to achieving earlier diagnosis would ensuring that sonographers are appropriately trained and received quality assurance

### **Accessing testing in the community**

The Women's Health Strategy encouraged the expansion of women's health hubs across England, with the aim of improving access to services and health outcomes for women. Women's health hubs alongside community diagnostic centres are important enablers to improve early diagnosis of ovarian cancer but to date have not been utilised as part of the diagnostic pathway for ovarian cancer.

The 10 Year Health Plan must look to have a more joined up approach to women's health care, utilising the tools and expertise already available in women's health hubs to improve early diagnosis of gynaecological cancers, ensuring women presenting with symptoms are able to access the pathway as soon as possible.

### **Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?**

#### **Challenges**

Data – there is a need for greater access to disaggregated data by cancer tumour type so that ovarian cancer is not grouped it with gynaecological cancers all of which have very different diagnostic and treatment pathways so aggregated data does not help identify areas for improvement. There is no access to data that covers the whole patient journey from diagnosis to treatment to follow up. Cancer data is also often delivered with a time lag

Genomics - Widespread access to genomic testing has improved access to personalised treatments and means that more women than ever before can find out whether there are implications for their family. There is increased demand on genomics services so ensuing that test results are available in time to make treatment decisions is crucial.

#### **Enablers**

##### **Data**

Within the 10 Year Plan there must be a commitment to making data available that is disaggregated by tumour type and timely. Having access to this data will allow us to understand the challenges across primary and secondary care.

## **Genomics**

There must be capacity in the system to allow for the expected growth of genomic testing to ensure that test results are delivered promptly to ensure that personalised treatment can be delivered effectively.

### **Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?**

#### **Women's health care concerns not taken seriously**

##### **Challenge**

When it comes to ovarian cancer one of the biggest challenges faced in spotting the illness earlier is the lack of symptom awareness among the public and GPs. Too often women's pain and discomfort has not been taken seriously in healthcare settings and women are not equipped with the information they need on ovarian cancer.

In England two thirds of women are diagnosed at a late stage when the disease is more difficult to treat. Awareness of symptoms is key to improving early diagnosis; however, we must also address the misconceptions around ovarian cancer to ensure more women experiencing symptoms visit their GP. Target Ovarian Cancer found that 40 per cent of women in the UK wrongly believe that cervical screening detects ovarian cancer. We need to see changes around the messaging for smear tests and ensure that women are given agency in their health and are confident seeking help when they feel something is wrong.

##### **Enabler**

Whilst we welcomed the Women's Health Strategy from the previous Government, and the ambitions set out to improve health and wellbeing of women and girls, we have seen little progress made against the commitments, such as NHS England's target to diagnose 75 per cent of cancer at stage I or II and improvement around awareness of gynaecological cancers and family history.

The 10 Year Health Plan must consider where accountability for women's health will sit, in particular where awareness and early diagnosis of gynaecological cancers will be addressed appropriately. With no viable screening programme, we must improve public awareness of ovarian cancer symptoms and invest in better screening tools to ensure we see more people with a gynaecological cancer diagnosed at an early stage.

#### **Access to primary care**

##### **Challenge**

Lord Darzi's report identified the difficulty experienced by the public accessing GP appointments, we welcomed the government's commitment to increase

the number of GPs and recognising the importance of primary care in tackling early diagnosis. However, too many women experience misdiagnosis and delays as a result of GPs not being appropriately educated or supported to diagnose ovarian cancer quickly. Target Ovarian Cancer found that 46 per cent of GPs believe that ovarian cancer presents in the late stages. This misconception, combined with a lack of knowledge and education on ovarian cancer can lead to more women receiving a late-stage diagnosis when the disease is more difficult to treat, and outcomes are poorer.

### **Enabler**

To help address the challenges in spotting illnesses earlier we must see investment in primary care, improving access to face to face appointments and ensuring GPs are appropriately educated to diagnose ovarian cancer, with clear guidance on when to request diagnostic tests and when to reinvestigate symptoms.

### **Making better use of existing screening and testing**

#### **Challenge**

Target Ovarian Cancer research has shown there is confusion around cervical screening with 40 per cent of women wrongly believing that cervical screening detects ovarian cancer. Ovarian cancer symptoms can often present as abdominal symptoms leading to a misdiagnosis of IBS or other abdominal conditions.

#### **Enabler**

Update cervical screening information so that it is made clear that it does not test for the other four gynaecological cancers and signpost to symptom information.

When ordering a FIT test for women over 50 with abdominal symptoms (bloating, abdominal pain, urinary symptoms and loss of appetite) a CA125 blood test should also be considered.

**Q5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example:**

#### **Short term within the next year:**

**Cancer strategy:** Target Ovarian Cancer alongside other charities in the sector have been calling for a long-term cancer strategy. International evidence shows that those countries with cancer strategies have been most

effective at improving outcomes for patients. We welcomed the announcement in October that the Government will look to publish a Cancer Plan, we hope to see this delivered within the next year with an opportunity for charities representing cancers to contribute to the plan, ensuring the voices of the patients we represent are heard. The cancer strategy must also enough resource for it to be delivered and an accountability for delivery must be clear.

**Women's Health Strategy** the Women's Health strategy should be reviewed and sufficiently resourced so that it can be fully implemented. As part of this a review of accountability for women's cancers must be considered.

### **Shorter diagnostic pathway with access to community diagnosis testing**

To ensure women with ovarian cancer get the tests they need and are able to start treatment as soon as possible we need to see the diagnostic pathway for ovarian cancer shortened. This change could be achieved within the next year by updating NICE guidelines in line with best practise in Scotland, where they already undertake the CA125 blood test and ultrasound at the same time.

**Cancer awareness:** Awareness around the signs and symptoms of ovarian cancer remain worryingly low and can often be misdiagnosed as IBS or menopause. Every four years Target Ovarian Cancer measure awareness levels across the UK and whilst we have seen some improvement around awareness of bloating and abdominal pain, we must go further to ensure everyone is able to recognise the symptoms of ovarian cancer. We welcomed previous iterations of NHS England's 'Help us, help you' in 2021, highlighting bloating and abdominal discomfort. We have been calling for consistent investment in awareness campaigns and are delighted that the 'Help us, help you' campaign will be focusing again on abdominal symptoms in 2025. With over half of women diagnosed at a late stage in England we must see continued investment in awareness campaigns, to help equip women with the information they need on ovarian cancer.

### **In the middle, that is in the next 2 to 5 year Long term change**

#### **Investment in ovarian cancer research for screening, treatment and prevention**

Within the next 2-5 years we must see better investment in screening tools and prevention options for ovarian cancer. With no viable screening programme, we rely on women and GPs being able to recognise the symptoms to receive an early diagnosis. Investment in the development of long-term research goals such as screening and ovarian cancer vaccine need to be considered over the next five years.

Through recent NICE guidelines on familial ovarian cancer more people will be able to find out if they have a genetic variation that increases their risk of ovarian cancer this means we need to see greater investment into preventive treatments as current

options are limited to surveillance or preventive surgery which can have significant side effects. There is a need for investment in research into prevention