

Identifying and breaking down barriers to early diagnosis of ovarian cancer in primary care:

Interventions and learnings



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Many women with ovarian cancer tell us about the challenges of receiving a diagnosis. Here is Helen's story:

“

I knew nothing about the symptoms of ovarian cancer – if I'd known I would have pushed to see my GP a lot earlier. When you get into your 60s, you think your body is supposed to change. Women don't know what the symptoms are. We all need to know.

The summer before my diagnosis, I began to experience pain in my abdomen. It felt similar to period pain, and I dismissed this due to my age. By December I was really bloated and experiencing both constipation and diarrhoea at one point or another. My father died of bowel cancer, so I knew I needed to see my GP.

I thought if I had anything it would be bowel cancer – I never had ovarian cancer in my mind. They initially suspected IBS but said they'd do a blood test due to my family history. This showed a high level of potassium, so I was sent for another test – which I now believe was a **CA125 blood test**.

I was later referred to a bowel specialist who informed me there were no bowel abnormalities but that I was being referred to the gynae team who sent me for a CT and **ultrasound**. By the end of the month, I was diagnosed with ovarian cancer that had spread to the spleen, lymph nodes and near my liver. This was a huge shock.”

Helen

This is why we must take action on ovarian cancer diagnosis.



Foreword

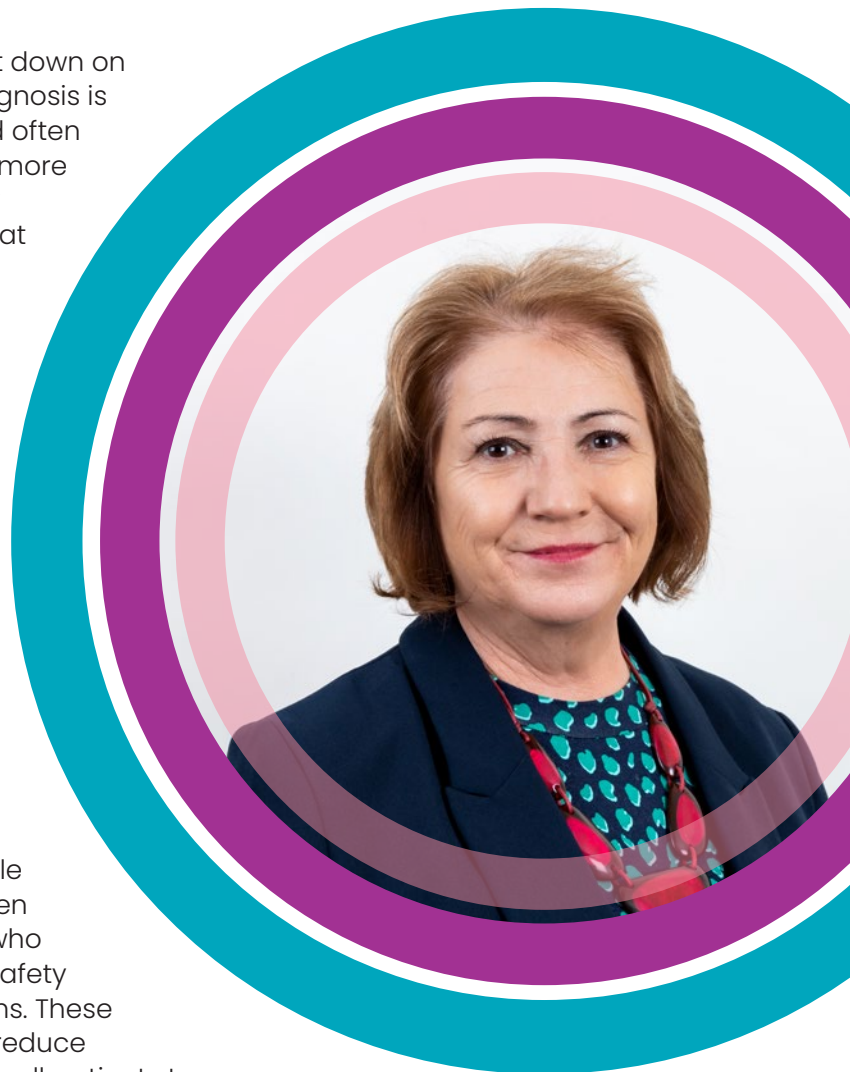
Those facing ovarian cancer are being let down on all sides: symptoms awareness is low, diagnosis is often too late, treatments are too few and often debilitating. The earlier the diagnosis, the more quickly treatment can begin. But we know that the proportion of women diagnosed at an early stage varies across England.¹

We recognise that there are challenges facing primary care in diagnosing ovarian cancer symptoms and setting women on the right pathway. However, the scale of regional variation indicates that improvements can be achieved. This is why we developed and launched a ground-breaking project to identify and address barriers to the early diagnosis of ovarian cancer.

By working together with primary care in three regions in England, our award winning² project has shown that technology can help primary care teams to consider and act confidently on possible ovarian cancer symptoms; to recall women with possible ovarian cancer symptoms who have not had a CA125 blood test; and to safety net women who have persistent symptoms. These are important, lifesaving actions that will reduce misdiagnosis and speed up referral of unwell patients to the right pathway for them. They can be implemented cheaply and simply and can become routine in any practice. Earlier diagnosis of ovarian cancer is possible anywhere in the UK and it is especially important that these interventions are adopted in those areas of the country that have comparatively low rates of early stage diagnosis.

This report outlines our learnings so far. We will continue to work in partnership to develop new tools and best practice and will report further findings later in 2023. These findings will be available via Target Ovarian Cancer's new Early Diagnosis Network, a place for everyone with a commitment to better diagnosis to come together, share learnings and improve practice.

We know that some UK regions have ovarian cancer survival rates that match the best in the world, and yet we currently have one of the poorest average five year survival rates.³ It is both vital and urgent that action is taken to address regional variation in diagnosis and ensure that everyone, regardless of where they live, has the earliest possible diagnosis and the best possible outcomes.

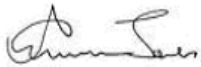


We would like to say thank you to our delivery and advisory partners:

- ▶ Project Board members – Dr Clare Stephens (Chair, phase 2) and Professor Sean Duffy (Chair, phase 1), Annwen Jones OBE, Dr Victoria Barber, Dr Neil Smith, Dr Pawan Randev, Kirstin Leslie and Dr Alison Wint.
- ▶ East Midlands – Dr Pawan Randev and Beena Abdul.
- ▶ Peninsula – Kirsten Leslie, Peninsula Cancer Alliance GPs and the participating PCNs, with particular thanks to Pathfields and Penwith.
- ▶ Pennine Lancashire – Dr Neil Smith, Angela Dunne, Julie Moorcroft, and Rossendale West, Rossendale East, Ribblesdale and Blackburn West PCNs.
- ▶ Target Ovarian Cancer project team – Dr Sharon Tate, Natalie Ritrovato and Catherine Pearson.

We would also like to thank the Peter Sowerby Foundation, whose funding made this project possible.

Together we can, and we will, save lives.



Annwen Jones OBE,
Chief Executive, Target Ovarian Cancer

Introduction

Primary care plays a vital role in getting the right diagnosis – the outcomes for women diagnosed via an emergency presentation at A&E are much poorer than those diagnosed through visiting their GP.

Research shows that the proportion of women diagnosed at an early stage (I or II) varies from 21.8 per cent to 62.9 per cent across England.⁴ Target Ovarian Cancer's report, **Pathfinder 2022: Faster, further and fairer** found that there are still too many delays along the diagnostic pathway and that GPs need more training and support.⁵

The NHS Long Term Plan⁶ in England sets out the aim to save thousands of lives each year by dramatically improving diagnosis. The key ambitions are that:

- ▶ by 2028, 55,000 more people each year will survive their cancer for five years or more.
- ▶ by 2028, 75 per cent of people with cancer will be diagnosed at an early stage. (stage I or II).

Since 2021, Target Ovarian Cancer has worked with primary care and cancer teams to implement simple interventions across three pilot sites around the country to target geographical variation, with the aim of improving early diagnosis of ovarian cancer. The piloted interventions were:

- ▶ A clinical IT alert.
- ▶ Retrospective audit search.
- ▶ Safety netting search tool.
- ▶ Targeted engagement and education approach.

This report summarises the implementation of these interventions, the impact in the areas of implementation and learnings that can be taken forward by teams in other parts of the UK.

Our partnership work proves that these interventions in primary care can make a difference. We need more NHS primary care teams to take part to reduce variation in the rates of early diagnosis, safety net more patients, and improve ovarian cancer survival rates.

This is why Target Ovarian Cancer is launching the first national network exclusively focused on the early diagnosis of ovarian cancer. Together, we will support ovarian cancer leaders to test out digital and educational tools; trial changes to processes; share ideas; and build a national evidence base of what works to transform the future for women affected by ovarian cancer.

Project outline

Research on barriers to early diagnosis

Our report **Identifying and breaking down barriers to early diagnosis of ovarian cancer 2021**⁷, looked in detail at the different approaches taken by five Clinical Commissioning Groups (CCGs) in England to ovarian cancer investigation and diagnosis to better understand these geographical inequalities.

Watch our animation to see what we found and how we are overcoming challenges in early diagnosis.

▶ **Watch animation**

targetovariancancer.org.uk/EarlyDiagnosis

The research found four areas where improvements could usefully be made:

- ▶ Local level data to drive improvement.
- ▶ Promoting the role of technology in early diagnosis.
- ▶ Best practice for safety netting symptoms and the referral pathway.
- ▶ Developing support for GPs to better understand the symptoms of ovarian cancer and the opportunities for earlier diagnosis.

These findings led to the development of the next phase of the project, giving a starting point for designing innovative solutions to meet these challenges.

Developing interventions

Following publication of our phase 1 report, we shared the findings with Clinical Commissioning Groups (CCGs), Primary Care Networks (PCNs) and GPs in England, and invited teams interested in testing new innovative approaches to support earlier diagnosis to contact us. 25 teams expressed an interest in working with us – this level of engagement was incredibly encouraging, especially given the pressures facing NHS teams at this time.

Target Ovarian Cancer sought partnerships in regions that have lower than average rates of early diagnosis. We identified three pilot sites, two with a focus on digital interventions and one with a focus on education and engagement.

- ▶ Pennine Lancashire Clinical Commissioning Group (Lancashire and South Cumbria Cancer Alliance) worked with us to co-develop and test a clinical IT alert, a retrospective audit search and a safety net search to improve patient management for EMIS Web. In Pennine Lancashire, 57 per cent of ovarian cancer diagnoses are at stage III and IV, putting it at the Cancer Alliance average; however, net one-year survival is below average. We worked with 17 GP practices across four Primary Care Networks.
- ▶ Peninsula Cancer Alliance worked with us to co-develop and test a clinical IT alert and a retrospective audit search to improve patient management. These tools were developed for both EMIS Web and SystemOne. The Alliance covers 1.7 million people who live in Devon and Cornwall. 65 per cent of ovarian cancer diagnoses occur at stages III and IV, one of the highest rates across Cancer Alliances. We worked with ten PCNs that had been identified as outliers in cancer outcomes and requiring focused quality improvement work.
- ▶ East Midlands Cancer Alliance worked with us to co-develop and test a targeted engagement and education approach to support primary and secondary care teams to connect, navigate and shorten the diagnostic pathway. Over 600 cancer cases are diagnosed per 100,000 people every year. By 2030 there will be some 238,000 people in this area living with and beyond cancer. 62 per cent of ovarian cancer diagnoses occur at stages III and IV.

The impact of the Covid-19 pandemic

At the start of the pandemic, the number of GP appointments plummeted, with widespread concern across the health system of unmet needs, missed opportunities and delays to diagnosis of illness.

The pressures on already constrained primary care capacity have been well documented. The impact on our pilots has been mixed. However, thanks to the commitment of our partners, the insight contained in this report reflects experiences across all three pilot sites.

Evaluation framework

Target Ovarian Cancer created an evaluation framework to ensure the programme could monitor the impact of each intervention against local collectable data. With pilot interventions running for around four to six months, it was unlikely in this timeframe that we would see a change in stage of diagnosis data sets. Therefore, to track the efficiency and efficacy of the interventions we monitored three indicators to see if and how they made a difference towards diagnosing ovarian cancer earlier. These indicators were:

- ▶ Numbers of patients contacted/actioned as part of the intervention.
- ▶ Number of referrals to secondary care.
- ▶ GP-reported confidence and feedback.

In addition, partners agreed to take part in case study interviews and evaluation events to gauge how easy it had been to deliver the interventions, any impact on primary care colleagues and how resource intensive the new tools were to embed and use.

Findings and learnings

This report outlines the early findings of the interventions rolled out in 2022 and indicates where they have made a difference in patient care as well as lessons for further roll out.

We are committed to working with our partners to evaluate the interventions as they continue to be used, so we can keep building a bank of case study information to support commissioning and primary care teams to put in place best practice in ovarian cancer diagnosis.

Interventions and evaluation

Clinical IT alert

► Description

An alert that comes up on screen (with advice to test CA125 and review NICE guidance) when a woman over 50 is coded with a new diagnosis of IBS or diverticulitis and there has been no recent CA125.

COULD THIS BE OVARIAN CANCER AND DOES YOUR PATIENT NEED A CA125 +/- IMAGING?

For more info PLEASE READ below guidance.

This patient is being coded with a new diagnosis of IBS/Diverticulitis and is aged over 50. NICE recommends clinicians consider measuring serum CA125 if a woman (especially those aged >50) reports persistent symptoms of abdominal distension, increased urinary frequency, and/or early satiety.

<https://www.nice.org.uk/guidance/cg122/chapter/1-Guidance#detection-in-primary-care>

OK

► Impact on clinical decisions

A clinical IT alert protocol for EMIS Web was developed and tested by four PCNs (17 out of 18 practices participated) in Pennine Lancashire between December 2021 and May 2022. Two GPs, four Physician Associates and six other clinical staff plus six administrative roles participated in the subsequent evaluation event.

10 PCNs in Peninsula Cancer Alliance agreed to be part of a pilot to test two separate clinical IT alerts – one for EMIS Web and one for SystemOne. Due to Covid-19 and other local pressures, the clinical IT alert was tested by seven GPs.

This alert helped GPs and Physician Associates in Pennine Lancashire recognise and confirm misdiagnosis in one woman.

100 per cent of primary care colleagues in Pennine Lancashire agreed that the clinical IT alert:

- Helped professionals consider ovarian cancer as a possible diagnosis.
- Was simple to use.
- Was a tool they wanted to keep on their system.

▶ Learnings from the clinical IT alert

While overall feedback was positive from those who had used the clinical IT alert, five GPs in Peninsula reported problems with loading the clinical IT alert on their system. One GP said they were sent a zip file but were unable to find the instructions for loading the protocol: **“We haven’t got any really IT savvy people at the surgery.”**

Primary care clinicians reported a growing risk of **“decision making tool fatigue”** as the number of pop-up alerts on their systems grow.

One pilot site manager told us: **“It is up to each practice whether they activate the protocol that runs the pop-up. We promote and encourage but can’t mandate, as a result pick up can be patchy. Also, too many pop-ups dilute the impact as clinicians become pop-up blind.”**

However, the manager also noted that, because of the relatively low incidence of ovarian cancer, pop ups will not be triggered in high numbers for any individual clinician. This means that this pop-up may be less distracting to clinicians.

▶ Case study 1

A woman presented with abdominal pain. She was coded with a diagnosis of diverticular disease, triggering the clinical IT alert. Upon reviewing the clinical IT alert, the GP was prompted to test CA125. The result was elevated. She was subsequently diagnosed with ovarian cancer, allowing her to access the care she needed.

The GP told us that the clinical IT alert is:



SMART in every way. Certainly, recommend to other practices as easily reproducible... It fulfilled PCN DES for early diagnosis of cancer... The pop up made doctors consider it as a differential diagnosis. This led to further risk assessment history and examination and additional CA125 tests that would not have happened without the prompt.”

Retrospective audit search

► Description

The retrospective audit consists of an audit search that brings up a list of women coded with a new diagnosis of IBS or diverticulitis in the last six months, with no recent CA125 result.

► Impact on clinical decisions

In Pennine Lancashire, 51 women were identified by the search, 24 contacted and 20 tested across four Primary Care Networks. Both the searches and patient communications were led by Physician Associates.

- 92.31 per cent of respondents agreed that this audit exercise helped to identify possible misdiagnosis.
- Practices reported that patients were keen to undertake the test and be checked, with very few reports of women declining, and seemingly only under circumstances where investigations for other conditions were ongoing.
- Feedback included that this created a beneficial learning exercise for all staff within the primary care team, and highlighted the symptoms, presentation, and importance of early recognition of ovarian cancer. This resulted in ovarian cancer being discussed at an organisational level more often.
- 100 per cent of participants agreed that their knowledge of ovarian cancer increased because of participating in the project.*

In Peninsula, the roll-out of the retrospective audit was affected by primary care capacity, the impact of Covid-19 and IT system challenges. Two PCNs and one practice completed the search within the original timeframe of the pilot.

One PCN's search using SystemOne identified 10 patients who met the criteria, two of whom were identified as being suitable for further investigation.

A second PCN trialled the search in one practice in preparation for roll-out across the Network using the EMIS Web system. This identified 41 women, aged 50-89, 10 of whom could potentially be offered a CA125 blood test.

Data from pilots of the retrospective audit searches in other PCNs will be reviewed in 2023 and shared with the Early Diagnosis Network.

* Attendees at our evaluation session were asked to rate their knowledge of ovarian cancer on a scale of 1-10 (1= the lowest; 10 = the highest) before the project started and on the day the evaluation was carried out. The average before knowledge score or respondents to both questions was 5. The average after knowledge score was 7.7. this increase showed an average after score shift of 2.7 points.

▶ Learnings from the retrospective audit search

One GP testing the audit told us that the retrospective audit search generated a long list going back 15 to 20 years, while the agreed protocol specified the previous six months only. This meant that the GP worked through many records which were not relevant and, consequently, he rated the search as unsatisfactory. The GP commented: **“I get lots of emails with different ideas for projects and it was a kind of search that came up as an idea... it was one of many.”**

Another recommended a focus on education for clinicians to embed CA125 into their standard practice, rather than a retrospective audit. He also recommended that:

- ▶ CA125 could be embedded in secondary care clinical practice as a standard blood test investigation for symptoms in women aged over 50 with a diagnosis of IBS or diverticulitis.
- ▶ Colorectal/Gastro two-week wait forms could insist on CA125 as part of the referral requirements for women aged over 50.

A third noted that the search is reliant on coding of the consultation for irritable bowel syndrome or for diverticular disease. An alternative study might search for women with abdominal pain coded as a presenting problem.

▶ Case study 2

A Physician Associate told our evaluation:



I saw a patient (over 70 years) who was having epigastric pain. She said she was diagnosed with IBS at 18. Because I was doing routine bloods, I asked to test her for CA125. And her CA125 was massively raised.”

The Physician Associate explained that she had the opportunity to add a CA125 blood test at a time when she was focused on the symptoms of ovarian cancer through her work on the pilot. She noted that without the pilot the patient would have been potentially missed. She also noted that the Physician Associate role is ideal for retrospective audit work – colleagues in administration or reception may be unable to answer patient’s questions and GPs have high workloads.

The Physician Associate also recommended that, before wider roll out, staff planning local delivery of the retrospective audit searches and contacting identified patients would benefit from hearing the learnings from the teams that delivered the pilots. A webinar format was recommended.

Safety netting search

► Description

A safety netting search through the GP practice system that identifies patients with a recent normal CA125 blood test result. These patients can be clinically reviewed and contacted if required to discuss if symptoms have persisted.

► Impact on clinical decision making

This search was carried out by four PCNs in Pennine Lancashire. 402 women were identified. 365 were contacted and given advice about persistent symptoms and returning to their GP.

- 100 per cent of respondents found the normal CA125 monitoring a worthwhile exercise for them and their patients.
- 100 per cent of respondents felt this helped to provide an effective safety netting system for women.

The workload was generally reported as positive and manageable. The Physician Associates reported positively on their experience of delivering this service.



Will continue to run the searches on a monthly basis, particular emphasis will be given to awareness month around ovarian cancer. Workload was manageable and easy to incorporate into monthly tasks.”



None of them (patients) knew what a CA125 was. They'd heard something about ovarian cancer maybe because it has been on the news lately, but they said they'd never really focused on it in terms of symptoms.”

► Learnings for safety netting search

The safety netting protocol was tested in Pennine Lancashire. It was evaluated positively, and no challenges were identified. This indicates that a review of safety netting practice would be a straightforward task for any PCN or Cancer Alliance looking to improve earlier diagnosis.

Education intervention

In the East Midlands, a need was identified for new ways to deliver guidance and advice between primary and secondary care teams in the investigations for ovarian cancer.

We have developed, in partnership, a series of videos that can be embedded in safety netting templates and used in other educational settings.

The clips provide bite-size, specific advice from a GP and a secondary care gynaecology cancer surgeon exploring common questions asked by primary care of Advice & Guidance services in hospitals when considering ordering possible ovarian cancer investigations.

The videos have been reviewed and found to be clear, concise and an excellent source of information for good practical content for primary care. Further peer review and testing is now underway, and further findings will be shared through the Early Diagnosis Network as they emerge.

Six keys to success

Six key factors affecting the usefulness of digital decision-making tools.

Our evaluation concludes that incorporating digital decision-making tools into primary care to facilitate earlier diagnosis of ovarian cancer requires six elements to be in place in the locality:

1

Leadership

The project should be led by someone who is trusted by PCN Cancer Leads and who has good insight into the local challenges that primary care faces.

2

Technology insight

When developing new digital tools and protocols, teams should prioritise ease of use for the primary care team. In Pennine Lancashire the tools were developed by the Digital Quality Team in the Commissioning Support Unit, who already had good knowledge of other tools locally available and access to systems for embedding resources within primary care systems remotely.

3

Skills development

For retrospective audit and safety netting reviews, it is helpful to assign the tasks to a dedicated group (for example, Physician Associates) and support them to develop confidence in communicating with patients.

4

Communication

Clear communication about the reasons for asking primary care to use digital clinical decision-making tools to ensure that there is local buy-in to testing the impact on the diagnostic pathway.

5

Data coding

PCN Cancer Leads need to ensure a consistent approach to coding symptoms and diagnoses across clinical and administrative teams.

6

Education

Training for primary care teams about the value of CA125 blood tests for managing and safety netting patients with symptoms of ovarian cancer.

Digital interventions: key learning

The evaluation process has involved conversations with both clinical and non-clinical staff working in Cancer Alliances and Primary Care Networks. These conversations confirmed that the pilot site teams value collaboration with Target Ovarian Cancer and welcome support to achieve local ambitions. Commitment across all three pilot sites to earlier diagnosis and improving survival rates is high.

Clinical IT alerts, risk assessment tools and data searches that can be adapted for ovarian cancer already exist within primary care systems. However, awareness of these tools remains low. Our pilots show that technical problems and 'decision making tool' fatigue, especially around the IT alerts, limit take up.

All three of the digital tools developed through our pilots were evaluated by primary care as effective support tools to diagnose patients who might otherwise be missed. The clinical IT alert received the most positive feedback of the three. Feedback from clinical staff managing the retrospective audit and safety netting searches showed that patients welcomed the contact.

In summary, the pilots have helped:

- ▶ Healthcare professionals to diagnose two women who would otherwise have been missed and improve their care.
- ▶ Increase clinical awareness, investigation and management of symptomatic ovarian cancer presentation underpinning and reinforcing good practice, as recommended by NICE guidance.
- ▶ Raise awareness of ovarian cancer symptoms among primary care teams and patients.
- ▶ Fulfilled Primary Care Networks' DES for early diagnosis of cancer.

Digital tools rely on coding and coding processes vary between practices. One pilot evaluation recommended that the Cancer Alliance in partnership with Target Ovarian Cancer provide a 'refresher' on good practice clinical coding.

The pilots found that leadership for early diagnosis of ovarian cancer is dispersed across different NHS structures and teams. While frontline primary care professionals will always be the start of the diagnostic pathway, opportunities for speeding up diagnosis will occur and be understood by different people at different stages. To be successful, focus on early diagnosis of ovarian cancer needs to be a shared ambition across each local cancer system.

The Early Diagnosis Network will provide free access to the protocols developed for EMIS Web, which was the most highly rated digital tool in the pilots. The network will oversee the roll out of these digital tools and provide a space for everyone committed to earlier diagnosis of ovarian cancer to collaborate and learn.

Future priorities

Our pilot projects have shown that digital alerts, audits and safety netting do identify women who may have been otherwise misdiagnosed. It has also shown that across primary care there is an appetite for targeted education on ovarian cancer symptoms, pathways and the barriers to early diagnosis within the health system.

Through delivering the pilots in areas that have lower than average early stage diagnosis of ovarian cancer, Target Ovarian Cancer has learned that the clinical leadership needed to reduce the time taken for ovarian cancer to be diagnosed or eliminated exists across different NHS professions and within both primary and secondary care settings. For these reasons, Target Ovarian Cancer is launching:



Target Ovarian Cancer's Early Diagnosis Network to bring together all healthcare professionals with an interest in improving diagnosis of ovarian cancer in the UK.

The Early Diagnosis Network is the first national network exclusively focused on early diagnosis of ovarian cancer. Together, we will support ovarian cancer leaders to test out digital and education tools, trial changes to processes, share ideas and build a national evidence base of what works.

We will build on the work of the three pilot sites by opening this to all Cancer Alliances and teams in England, Wales, Scotland and Northern Ireland working on earlier ovarian cancer diagnosis. Subject to funding, we aim to support more areas with lower than average early stage diagnosis of ovarian cancer. As a national charity, Target Ovarian Cancer will ensure that the insight and learning generated by the Early Diagnosis Network is shared with national policy makers as well as supporting local projects.



Target Ovarian Cancer's Early Diagnosis Toolkit.

We will produce a series of how to guides and tools to help primary care teams to implement and evaluate simple interventions, that can be adapted to local understanding and priorities. We will continue to work with teams across the UK to develop, test and share further best practice.

Join Target Ovarian Cancer's Early Diagnosis Network

Target Ovarian Cancer invites any healthcare professional working to improve the diagnosis pathway for ovarian cancer to join the Early Diagnosis Network and use the toolkit resources to improve the rate of early diagnosis in your area.

[▶ Join the Early Diagnosis Network here](#)

Together, we can change ovarian cancer diagnosis.

End notes

1. The Ovarian Cancer Audit Feasibility Pilot (2020) Ovarian Cancer Audit Feasibility Pilot Geographic variation in ovarian, fallopian tube and primary peritoneal cancer treatment in England. Available at: http://ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/ovarian_cancer_audit_feasibility_pilot_outputs
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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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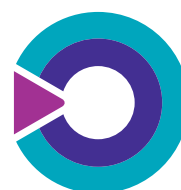
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