Identifying and breaking down barriers to early diagnosis of ovarian cancer

TARGET
OVARIAN
CANCER

Contents

Foreword

Ovarian cancer has a devasting impact – nationally, one in five people with ovarian cancer die within three months of diagnosis.

However, there is a 'postcode lottery' inequality in place when it comes to a diagnosis of ovarian cancer – shockingly, the proportion of women diagnosed at an early stage (stage I and stage II) varies in England from 21.8 per cent to 62.9 per cent, depending on where they live.

Statistics like these highlight the urgency for ovarian cancer to be recognised as a significant national priority.

In the development of this report, views and data were sought from a range of sources. This includes a significant amount of intelligence from GPs working on the ground. This has provided a unique and valuable insight on the specific challenges in leading patients to a speedy diagnostic pathway. Capturing this feedback has paved the way in identifying key areas for further exploration and learning for primary care systems, as explored in the report conclusions.

The information contained within this report does not highlight a single finding as a recommendation for improvement, but rather a detailed summary of learning. An early cancer diagnosis is dependent on multiple factors, and the individual components of these are examined at length within this work.

What this report does provide, distinctly, is a pivotal call to action for primary care systems: to step forward, review current practice and identify the routes to better outcomes. **Action needs to be taken to ensure excellent care, everywhere**.

The report also acknowledges that in the quest to dig deeper, considerable gaps and variation were found locally in data and knowledge. This further highlights the need for improvement and greater standardisation of practice.

In a changing NHS landscape, and one future-focused on better integrated partnerships between systems and a reduction in health inequalities, shining a spotlight on the regional variation in diagnosis of ovarian cancer is more important than ever.

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Action needs to be taken to ensure excellent care, everywhere

Identifying and breaking down barriers to early diagnosis of ovarian cancer

About this report

In the UK, each year 7,400 women are diagnosed with ovarian cancer. Unfortunately, most patients with ovarian cancer will receive their diagnosis late, at stage III or IV. Like all cancers, the earlier ovarian cancer is diagnosed, the easier it is to treat, and the greater the chances of survival.

The aim of this report is to present the findings and recommendations of the ovarian cancer diagnostic pathway research work undertaken by **Target Ovarian Cancer**, with an ambition to end the 'postcode lottery' in early diagnosis. This work has been completed as part of a transformational grant, funded by the **Peter Sowerby Foundation**. Target Ovarian Cancer is the UK's leading ovarian cancer charity, with an established history of leading primary care collaboration to support earlier diagnosis, since 2008.

This report and its findings will be of crucial reading to a wide range of stakeholders across England, including Clinical Commissioning Groups, Integrated Care Systems, Cancer Alliances, primary care professionals, and any organisation or persons responsible for the planning, implementation and use of ovarian cancer diagnostic pathways.

Challenges to early diagnosis

Ovarian cancer is often mispresented as a 'silent killer' in the media, as it's often claimed symptoms are only present in late-stage cancer. And when symptoms of ovarian cancer are present, they are sometimes labelled as 'vague'. Neither of these statements are true. This misinformation is particularly unhelpful, as it perpetuates the myth that neither primary care nor patients can expedite an ovarian cancer diagnosis.

The key symptoms of ovarian cancer are:

- Persistent abdominal distension
- Early satiety and/or loss of appetite
- Pelvic or abdominal pain
- Urinary urgency and/or frequency

Symptoms can also include:

- Unexplained weight loss
- Unexplained fatigue
- Unexplained changes in bowel habit

Some tell-tale physical signs of other cancers, like a palpable lump, will likely prompt a swift and confident GP urgent referral. The symptoms of ovarian cancer, like bloating, and discomfort after eating, can mimic other conditions, like IBS.

This means there's often a risk of misdiagnosis and inappropriate referrals for patients, all while the early diagnosis clock is ticking.

Good detective work, such as tracking and flagging symptoms, or identifying and ordering the correct investigative tests, is required by clinicians to spot and diagnose ovarian cancer early.

Given the presentation challenges of ovarian cancer, and the fact there isn't a national screening programme in place, we might start to think we've understood some of the reasons for the late diagnosis statistics.

However, these factors are just one piece of the puzzle.

What these factors can't explain, is **significant regional variation**.

Regional variation

Data has identified **serious geographical inequalities** within England.[1] Alarmingly, the proportion of women diagnosed at an early stage (stage I and stage II) varies from 21.8 per cent to 62.9 per cent, depending on where they live (measured by CCG).

This means there is a postcode lottery for ovarian cancer diagnosis. There can be a wide variety of reasons for regional variation in early diagnosis, including; age, patient symptom awareness, GP knowledge and experience and the time taken on a diagnostic pathway.

In response to this information, as the UK's leading ovarian cancer charity, we set ourselves a task to find out why. We took a deep dive and researched the different geographical approaches to ovarian cancer investigation and diagnosis. We wanted to take a look at best practice that can be replicated across the country to improve early detection and ovarian cancer outcomes.

1. The Ovarian Cancer Audit Feasibility Pilot (2020) Disease Profile in England: Incidence, mortality, stage and survival for ovary, fallopian tube and primary peritoneal carcinomas (Data from 195 CCGs). 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

Research aims

Our research was funded by the Peter Sowerby Foundation and carried out by medeConnect, a leading provider of qualitative and quantitative health research, on behalf of Target Ovarian Cancer.

In this research, we aimed to:
- Understand how the ovarian cancer diagnostic pathway and its implementation varies between CCGs.
- Understand how the techniques of the highest performing CCGs could be replicated across the country to improve diagnosis in poorer performing areas.
- Develop and test interventions to improve ovarian cancer diagnosis, in partnership with primary care.

Research methodology

We wanted to understand any differences in regional diagnostic pathways. For us to pinpoint and understand what best practice looks like, we needed to understand the key differences in approach from CCGs with contrasting early diagnosis data.

Selection

From our selection mapping, CCGs in England were ranked according to the proportion of stage I and II diagnoses combined as the primary metric, with one-year survival used as a secondary selection measure. For our selection process, we also considered the population demographics of CCGs (the proportion of those aged 50 years and over) and the geographical classifications of an area (if it was rural or urban).

From this list, we selected two CCGs from the highest performers, and three from the lowest performers to take part in our research.

Qualitative approach

Once our CCGs were ranked and selected, for us to understand the full picture of regional differences within each area, we took a deep dive into local intelligence.

We asked GPs, Commissioners, Cancer Leads and other staff focused on delivering the cancer agenda to tell us about their local ovarian cancer pathways, and discover if there was any local focus on improving ovarian cancer outcomes.

Interviews were carried out face to face and via video call, with the majority undertaken from January – March 2020. Some interviews were delayed until Autumn 2020, due to the Covid-19 pandemic. Interviews ranged from 40-80 minutes and a full analysis of findings was undertaken.

In total, we recorded 24 interviews with stakeholders. We asked key questions, like;
- How frequently is service commissioning reviewed?
- What are the local population demographics?
- How often are ovarian cancer datasets reviewed?
- What does the diagnostic pathway look like?
- What barriers are there to early diagnosis?

The analysis of findings was based on the audio recordings and interviewers' notes.

Quantitative approach

We surveyed 1,000 GPs nationally via a survey through CCGs and the Doctors.net community, seeking their opinions on ovarian cancer diagnosis and to find out more about any regional variations in approaches to diagnosis.

Desk research

We also looked for the mention of ovarian cancer in our selected CCGs' Governing Board meeting notes, of those that were publicly available. We looked for the mention of any local projects focused on ovarian cancer, or for ovarian cancer to have been highlighted for improvement over the past three or more years.

Covid-19 challenges and considerations

- Covid-19, and the resulting additional primary care pressures of the pandemic, presented a significant challenge in conducting our qualitative research.
- Additionally, the project was further complicated by a major restructure of CCGs in April 2020. Two of our planned participant organisations underwent mergers.
- These factors made it challenging for our research partner to establish connections to conduct interviews and some CCGs initially nominated to contribute to research found it difficult, or were now unable, to participate.
- To mediate this issue, we identified an additional CCG to interview, fitting our original selection criteria.

Research considerations

- Conducting small-sample research presents various challenges. Our interviews represent the views of individuals and local organisations, so findings are unlikely to represent the primary care workforce as a whole.
- The rarity of ovarian cancer is also a significant factor. Views and behaviours of GPs may be based upon limited experience in recognition and referral.
- For this study to be as reflective as possible, methods were undertaken to mitigate challenges, including GPs selected at random within CCGs to contribute to the research.
- Participants were blinded as much as ethically possible in providing interviews to avoid self-selection bias. However, professionals willing to have an in-depth interview about the diagnostic pathway are likely experienced.

Research findings

There is limited reported variation in diagnostic pathway practice and behaviours

Our research demonstrated very few reported variations in GP diagnostic pathway access and behaviours. The NICE NG12 recommendations were familiar and implemented universally within our research sites. Some GPs reported prompts on clinical systems to remind them to adhere to protocols.

GPs noted offering external examinations for masses routinely and detailed that a discernible mass felt on physical examination would lead to an immediate referral onto the two-week wait pathway. Opinion was divided on the benefit of internal examination.

> *"I don't think there is much point to do an internal examination. You need to have years of gynaecological training to understand everything. I would probably end up misinterpreting and delaying the process. I would do an abdominal examination to check for a mass."* – **GP**

There was very little negative feedback from our interviews in reference to the push-back of test requests. GPs reported that they are familiar enough with the referral system so as to be able to get their patients scanned when they have concerns. GPs told us they will request CA125 and ultrasound scans immediately if they are concerned that symptoms indicate ovarian cancer.

> *"Sometimes, if you put just bloating onto the request, radiology will bounce the request back. You learn from experience to put in other things if you strongly feel the patient needs it. The radiology department has a telephone line you can call if you are unsure"* – **GP**

GPs reported few barriers in access to diagnostics, although one GP did note a local variation in limitation of testing.

> *"Certainly in younger women I've said 'let's do the blood test' and not been able to do it. They are much stricter and the CCG always seem to be funded less and they put more blocks in for investigations done in primary care."* – **GP – speaking about CA125 testing**

Patient non-attendance at secondary care appointments was reported to be a very rare occurrence and GPs noted the importance of highlighting the expectations of a booked appointment to patients.

Rapid diagnostic/vague symptom pathways are valuable to GPs

Our research found that GPs reported confidence in using the two-week wait diagnostic pathway but highlighted it can often be difficult to decide the appropriate route for patients with symptoms that do not meet the specific criteria for referral.

> *"Honestly, I can't give you a figure. But from past experience sadly patients with ovarian cancer are more often than not diagnosed either via non-NG12 referrals than not, they've come to the surgery or gastroenterology or gynaecology and so on and finally they are diagnosed with ovarian cancer, finally there is of course the emergency presentation. We have gradually become aware with NG12 and awareness campaigns run from time to time. If I were to hazard a guess, I wouldn't be surprised if it was a third via AE."* – **GP**

GPs with vague symptom pathways implemented in their local areas valued them and agreed that they should be available in every part of the country.

Traditional GP/patient relationships and appointments are changing

> *"When I started, I knew most of my patients without looking at their notes, if I may say so, I knew my patients very well and they had continuity. At the present where I work, I'm afraid it's very much what's presented to me and I have to get on with it."* – **GP**

Clinicians in our research highlighted some of the challenges in changing relationships for GPs and patients. They noted the idea of a regular relationship with a 'family GP' as diminishing, which means maintaining continuity of care can be challenging. Covid-19 fast-tracked the adoption of primary care remote triage and digital consultations at an incredible pace. However, it's highly likely that many of the methods that have been piloted out of necessity during the last two years are here to stay.

The role of technology in primary care is becoming more predominant

Digital systems to reflect new ways of working and support GPs to faster diagnosis were highlighted in our research.

In one of the CCGs that diagnoses more cases of ovarian cancer at an earlier stage, we found that a significant intervention had been put in place. This CCG commissioned an Ardens template which prompts GPs to order a CA125 test if a new diagnosis of IBS for a patient aged over 60 is entered into the clinical system.

> *"I suspect for a newly qualified GP it is a nice safety net or for someone who don't know their list that well."* – **GP, speaking about the Ardens template**

Our research also highlighted technological challenges and areas for improvement. GPs told us that variations in data quality present challenges. Keyword searches were noted to often be a significant part of tracking symptom presentation or identifying family history. Keyword use and clinical coding by colleagues were noted as not sometimes as good as they would like them to be.

General awareness of symptoms is low

> *"Generally, I think that awareness of ovarian cancer is very low compared to other cancers."* – **GP**

Our research highlighted that early symptom presentation from patients remains a significant and ongoing concern for primary care.

GPs noted that patients rarely request CA125 tests, and do so to a much lesser extent in comparison to other investigations, for example, prostate-specific antigen testing (PSA).

Recognition of ovarian cancer symptoms in elderly/co-morbidity patients can be challenging

Our research highlighted a need for particularly astute detective work from primary care in identifying ovarian cancer symptoms in elderly patients, and/or those with co-morbidities. GPs in our interviews were concerned about the danger of symptoms being masked when the option of several causes is present.

> *"The main trick is taking good history, especially those presenting multiple times. It is known that lack of continuity in primary care is a problem so listening to patients is crucial."* – **GP**

Most GPs reported that they usually err on the side of caution and test regardless, however, they were conscious of their role as a gatekeeper to the diagnostic pathway and felt mindful of not overloading diagnostic services.

> *"We are all aware in primary care that the cancer detection rates are not as good as they should be, in the UK generally compared to other countries. Once in treatment, the outcomes are comparable, but the outcomes are related to early detection. So when I'm seeing somebody these things are going through my mind... part of my job is not to refer everyone to the cancer pathway because it would be overwhelmed, but on the other hand part of my job is to find that person who needs to be referred."* – **GP**

Standardised guidance to flag and action test results is lacking

A significant finding of our research was that processes for flagging and actioning test results can vary from practice to practice. These processes are not derived from CCG or other guidelines, but reflect the way individual practices are managed, and so processes do vary. In this area of research, locums highlighted significant challenges in accessing requested test results.

> *"It depends on the system. In some practices all the results go to an on-call doctor and they will have to divvy it up amongst themselves; and I have worked as a locum in a practice where results have sat there for weeks and weeks for me to get back there to look at them, which is a concern. They're just stuck in a folder with the doctor's name who requested the blood test."* – **Locum GP**

Conclusions and key learning

Regional variation in detecting ovarian cancer is down to more than just pathway design

Our research found that there were very few differences in the design and implementation of the patient pathway between the high and low performing CCGs. This tells us that there is more at play for early diagnosis than just access to diagnostics and referral processes.

GPs in our research felt comfortable trusting a hunch, knowing when and how to push through a referral for a patient with a high index of suspicion. Our interviews also demonstrated little push-back from secondary care for test requests, and when challenges were present, GPs felt confident in using their experience and knowledge to expedite a patient.

The impact of Covid-19 has presented barriers to early diagnosis

The effects of Covid-19 pressures were reported within our research, and some GPs told us they felt the minimum criteria for diagnostic tests had changed within this period, alongside increased access delays due to limited secondary care capacity.

Safety netting underpins every element of early diagnosis in primary care, and it's more important than ever

Both the higher and lower performing CCGs agreed on many of the ways in which systems could be strengthened to improve ovarian cancer detection.

A common theme in our research findings was safety netting. With the move to remote consultations and the disbandment of a 'family GP' approach to care, robust safety netting is more important than ever. It's important that primary care recognises and utilises digital safety netting systems that are available to help support recognition and referral. There are different options for safety netting systems available that can be easily integrated into GP IT. For primary care to successfully recommend and implement a safety netting system, the principal focus should be to maintain continuity of the diagnostic pathway across the multiple professionals a patient may see.

Ovarian cancer is not a focus at CCG Governing Board level meetings

Our desk research looked at the level of focus being given to ovarian cancer at our five selected CCGs' Governing Board meetings. We found no evidence of discussions related to ovarian cancer in relation to systems improvement or focus. This could mean that ovarian cancer data is not being reviewed regularly enough to assess performance and identify potentially significant issues. Passing references to cancer management in general were noted, and we found one CCG made a mention to ovarian cancer in the context of public awareness.

Patient awareness of symptoms needs a national focus, but GPs need to be prepared for when patients present

"Patient recognition of symptoms is lacking; they often ignore low-level symptoms. We are continuing to work with primary care to recognise those low-level symptoms and importance of previous presentations." – **CCG Cancer Lead**

GPs noted that patient awareness of symptoms remains a challenge – a reliance on patients to present early to primary care with symptoms can pose a significant barrier to early diagnosis.

Systems need to be in place to ensure that when patients do present, recognition and referral systems and processes are in place to make early diagnosis a smooth, safe and supported journey.

GPs are the key driver in prompting a CA125 investigation

Our research found that GPs rarely had requests from patients for CA125 testing. GPs noted that CA125 isn't as regularly requested by patients as a PSA test, and the patients that are bringing ovarian cancer into conversation are younger and have better digital skills, being more likely to Google symptoms before booking an appointment. Given that ovarian cancer is more of a risk in older cohorts of patients, GPs need to be especially mindful of recognising symptoms and the correct diagnostic tests to request for patients who may not have the same digital skills.

Effective clinical coding underpins systems, processes and planning

GPs in our study noted that clinical coding can vary between clinician and practice, and that searches, for both auditing and data analysis, rely on primary care staff inputting the same codes. GPs acknowledged that it can be difficult to search systems for recorded symptoms if colleagues have used different codes or terms to the ones they would use.

Clinical data must also be recorded accurately and consistently to support monitoring and planning of services. Databases are only as good as the information contained within them.

Locum GPs need universal access to systems and tests, with robust safety netting in place to prevent system failures in reviewing and actioning results

Our research highlighted some significant challenges for locum GPs in accessing systems, tests and results. Locums take their roles and responsibilities very seriously, and systems and processes need to be in place to support their specific needs. Some respondents in our research commented that the test request systems they had access to while working as a salaried GP, took a long time to gain access to while practicing as a locum.

"You have to be a regular doctor because it can take months to get ICE access. It is an IT access problem. Same thing with Leeds care records, I only have access to those when I am salaried, not as a locum." – **Locum**

Locums also highlighted significant challenges in being able to review and action test results. There is a danger of tests becoming 'lost in the system', leading to missed or late diagnosis. Effective systems need to be in place to avoid this issue. Universal guidance on this subject would benefit all clinicians, no matter where they work or how often they work, so that they are supported by mindful processes to minimise risk to patients.

GPs are aware of the challenges of presentation in elderly patients, and those with co-morbidities

Our research highlighted the challenges for GPs in recognising the symptoms of ovarian cancer in patients where there could be a number of potential causes.

Given that most cases of ovarian cancer occur in post-menopausal women, and that more than half of cases are those aged over 65, our research has recognised a significant cohort vulnerable to the risk of delayed diagnosis and misdiagnosis.

GPs reported significant value of support from secondary care on borderline cases or persistent symptoms with negative test results, naming services such as Consultant Connect.

The importance of education to the wider practice team was highlighted. One GP noted that there would be great benefit in each member of practice staff being trained to recognise the symptoms of ovarian cancer, so that they can signpost effectively.

> *"Educating GPs but especially nurses who may see some patients more than GPs as are receptionists. Prompt them to think about the right things so that patients are not missed i.e. prioritising what patients want to discuss or is their biggest issue."* – **GP**

The national roll-out of Rapid Diagnostic Centres and the timed pathway for ovarian cancer will be valuable to early ovarian cancer diagnosis

We found GPs value the Rapid Diagnostic Centres in providing a pathway for patients where two-week wait referral criteria can be stringent.

The NHS Cancer Programme Recovery Plan has also recently announced the intent to establish a new timed pathway for ovarian cancer, like those already established for lung, prostate, colorectal and oesophago-gastric cancers.

Effective utilisation of these pathways will help support GPs to refer patients onto the appropriate pathway to earlier diagnosis.

Our next steps

This is just the start of our journey. Equipped with our research findings and resulting recommendations, we're ready to launch phase two of our project– practical implementation. We'll be working with Cancer Alliances and CCGs directly to develop and test interventions aimed at breaking down barriers to early diagnosis.

We'll be focusing on these four key areas:

1. **Using local level data to drive improvement**

2. **Best practice for safety netting symptoms and the referral pathway**

3. **Promoting the role of technology in early diagnosis**

4. **Developing support for GPs in readiness for the upcoming timed ovarian cancer pathway**

This project and its outcomes will be reinforcing the NHS Long Term Plan aim of 75 per cent of cancers being diagnosed at stages I and II by 2028.

If you have any questions about this report, project, or would like to partner your organisation with us to create excellent care, please contact:

commissioners@targetovariancancer.org.uk

To find out more about Target Ovarian Cancer's resources for GPs, and to access our educational resources, please visit: targetovariancancer.org.uk/cpd

Target Ovarian Cancer would like to thank **The Peter Sowerby Foundation** whose generosity made this research possible.

Target Ovarian Cancer is the UK's leading ovarian cancer charity. We've been collaborating with primary care to promote earlier diagnosis for over a decade. We want to support health professionals to create excellent care, everywhere.

To find out more, visit:
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