TARGET OVARIAN CANCER
For every woman. For life.

Regional variation in the diagnosis of ovarian cancer in England

Contents

Foreword

One-year survival for ovarian cancer in the UK trails that in other countries.[1] This suggests that lives are being lost because we are not diagnosing ovarian cancer soon enough.[2] With that in mind, Target Ovarian Cancer created the GP Advisory Board in 2014 to drive forward improvements in the early diagnosis of ovarian cancer.

To start with, we wanted to better understand what early diagnosis looks like in different parts of the country and this report examines three key indicators:

- The use of diagnostic tests
- Stage at diagnosis
- One-year survival rates

While our remit is UK wide, to start with we have looked at England only based on the availability of relevant data, but we want to progress to examining the diagnosis of ovarian cancer across all four nations.

As health professionals we all have a responsibility to strive for improvement, looking to others to learn lessons where we can, and always looking to ourselves and our own practice to see what more we could do.

We have deliberately focused on the best performing areas – those places where we can seek to learn – rather than getting drawn into fault finding. It is our intention to start a conversation about what it is that enables some areas to lead the way in diagnosing ovarian cancer sooner and what the rest of us can do to follow them.

Too many women die of this dreadful disease. The power lies in our hands to change that.

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Chair, Target Ovarian Cancer GP Advisory Board
Senior National GP Advisor, Care Quality Commission

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Executive summary

Ensuring more women are diagnosed sooner is critical if we are to see significant improvements in survival rates for ovarian cancer.

This report by the Target Ovarian Cancer GP Advisory Board explores regional variation in the diagnosis of ovarian cancer. It looks at how many diagnostic tests are being ordered. It looks at the stage at which women are being diagnosed with ovarian cancer and it looks at survival rates. All of these are broken down by Clinical Commissioning Group (and in one case by Primary Care Trust).

It finds large variation in the number of CA125 blood tests carried out in each area, with 90 times more tests per 1,000 practice population in the area with the highest number of referrals compared to the lowest. There is also significant variation in the time taken to complete non-obstetric ultrasounds, with over 80 per cent of tests completed within a fortnight in some areas compared to almost zero in others.

There is comparable variation in the number of women diagnosed with early-stage disease. In some parts of the country this is over half, in others just one in five.

Finally, there is variation in one-year survival rates, ranging from over 90 per cent in some areas to less than 60 per cent in others.

Some variation may be due to differences in local populations. For example, in areas with an older population it is likely that more CA125 tests would be ordered and in areas with a younger population there may be more borderline and germ cell tumours in women diagnosed with ovarian cancer, which typically have a higher survival rate.

The remaining variation may be explained firstly by differences in awareness of the symptoms among women in the population and their likelihood to present early. GP knowledge is a second significant factor and the third is local health systems; whether or not GPs are able to refer women promptly for the tests they need.

The following steps need to be taken to address each of these three areas:

- **Work to raise awareness among women of the symptoms of ovarian cancer** so they know what to look out for and when they should go to their GP.

- **Investment in GP training** to ensure all GPs know the symptoms and diagnostic pathway for ovarian cancer.

- **Improvements to the diagnostic pathway** itself to shorten the time it takes for ovarian cancer to be diagnosed or ruled out.

These simple changes could save lives. The aim of this report is to start a conversation about what different parts of the country can do to learn from one another and to ensure all women have the maximum chance of surviving this disease, wherever they live.

Introduction

'Achieving world-class cancer outcomes: a strategy for England 2015-2020' and its subsequent implementation plan place heavy emphasis on the importance of diagnosing cancer early:[3,4]

> *"Diagnosing substantially more cancers earlier could be transformative in terms of improving survival, reducing mortality and improving quality of life."*
> (Achieving world-class cancer outcomes: a strategy for England 2015-2020: 26)[5]

> *"Earlier diagnosis makes it more likely that patients will receive treatments which can cure cancer. It saves lives."*
> (Achieving world-class cancer outcomes: taking the strategy forward: 8)[6]

With this in mind, this report looks at three key indicators in relation to early diagnosis across England.[7]

- **Diagnostic tests** (CA125 blood test and non-obstetric ultrasound) – these indicate whether GPs in an area are considering ovarian cancer as a possible diagnosis in symptomatic women, and the speed with which tests are carried out indicates how quickly cancer is being diagnosed.

- **Stage at diagnosis** – the stage at which women are diagnosed shows the balance between early and late diagnoses in an area.

- **One-year survival rates** – one-year survival is an indicator of how early women are being diagnosed.

This report takes data published by NHS England and the National Cancer Registration and Analysis Service (part of Public Health England) and examines these three indicators across England. In some places data is still broken down by Primary Care Trust, but the majority of the information is now available by Clinical Commissioning Group (CCG) following the NHS reforms introduced by the Health and Social Care Act 2012.

It finds substantial variation between areas.

Diagnostic tests

The National Institute for Health and Care Excellence (NICE) pathway recommends that women with suspected symptoms of ovarian cancer are referred first for a CA125 blood test, then, if this shows raised levels of the CA125 protein, an ultrasound.[8] The exception is if ascites or a pelvic or abdominal mass are found upon physical examination, in which case women receive an urgent, two-week wait, referral.

While there is no right level of testing, regional variation can be an indicator of differences in professional practice in certain areas or variation in the adoption of NICE guidelines on the diagnosis of ovarian cancer:[9]

> *"From a population perspective, it is important to consider whether variation in the rates of testing reflects under-use or over-use of a technology, or whether it is linked to the clinically indicated level of intervention."*
> (NHS Atlas of Variation: 20)[10]

Table 1 shows that the highest rate of CA125 testing was 9.0 per 1,000 practice population. This compares to the lowest rate of 0.1 per 1,000 practice population. (While the latest available, the data provided is for Primary Care Trusts (PCTs) as it was collected prior to the introduction of CCGs following the Health and Social Care Act 2012.)

There were 90 times more tests per 1,000 practice population in the area with the highest number of referrals compared to the lowest.

It is worth noting that if the five PCTs with the highest referral rates and the five with the lowest referral rates are excluded, this range narrows to 8.4-0.9 per 1,000 practice population.[11]

Table 1: GP referrals for CA125 blood test by Primary Care Trust (2012)

Primary Care Trust	Estimated annual rate of referrals per 1,000 practice population
Redcar and Cleveland	9.0
Portsmouth City Teaching	8.9
Milton Keynes	8.7
Dorset	8.7
Great Yarmouth and Waveney	8.4
Herefordshire	8.4
Buckinghamshire	8.3
East Sussex Downs and Weald	8.1
Oxfordshire	8.1
Northumberland Care Trust	7.9
...	
Lowest referral rate	0.1

Source: NHS Atlas of Variation in Diagnostic Services (Data was missing for 10 PCTs).[12]

Diagnostic tests (continued)

If a woman is found to have raised levels of the CA125 protein, she is then referred for a non-obstetric ultrasound. This takes the form of either an abdominal or pelvic (transvaginal) ultrasound or both and enables the ultrasonographer or radiologist to check for any changes in the ovaries. Non-obstetric ultrasound refers to any ultrasound ordered for reasons other than pregnancy, including in cases of suspected cancer.

Table 2 presents data on non-obstetric ultrasounds. It shows how many tests are ordered and how long GPs are waiting by CCG. (Although it is not possible to separate out those tests specifically for suspected ovarian cancer.)

The number of tests completed within a fortnight of referral by a GP ranges from over 80 per cent in some CCGs to close to zero in others.

Table 2: GP referrals for non-obstetric ultrasound tests completed within 0-14 days by Clinical Commissioning Group (2015-2016)

Clinical Commissioning Group	No. of tests completed within 14 days	Percentage of total CCG referrals	Total number of referrals per annum
NHS Newham	3805	82.5	4615
NHS Eastern Cheshire	1925	78.9	2440
NHS Hounslow	2205	73.4	3005
NHS Bolton	990	70.5	1405
NHS North and West Reading	325	69.9	465
NHS South Reading	620	67.4	920
NHS Nottingham City	320	66.7	480
NHS Wokingham	500	65.8	760
NHS Horsham and Mid Sussex	495	53.8	920
NHS Newbury and District	385	52.7	730
...			
Lowest two week completion rate	45	3.8	1190

Source: Diagnostic Imaging Dataset.[13] Those CCGs where data was missing for more than 20 per cent of cases, or where data on the time taken to complete tests was missing in more than 20 per cent of cases have been excluded. This means a total of 168 out of 209 CCGs are included in the analysis.

Stage at diagnosis

The earlier a woman is diagnosed with ovarian cancer, the greater her chances of surviving one year or longer. Overall, one-year survival for women diagnosed with ovarian cancer between 2009-2012 was 76.5 per cent.[14] One-year survival is highest for women diagnosed with stage I disease at 98.7 per cent, but decreases with each subsequent stage of disease and is just 51.4 per cent for women diagnosed with stage IV ovarian cancer.[15]

In total, 35.1 per cent of women with ovarian cancer are diagnosed at stage I or II compared to 47.4 per cent who are diagnosed with stage III or IV ovarian cancer (stage data is missing for 17.5 per cent of cases).[16] Table 3 shows the breakdown of early stage diagnoses by CCG.

In some parts of the country over half of women are diagnosed with early stage disease, but in some areas this drops to fewer than one in five.

Table 3: Proportion of early stage diagnoses by Clinical Commissioning Group (2012-2014)

Clinical Commissioning Group	Early stage diagnoses		Total cases
	Cases	Per cent	
NHS Haringey	30	55.6	54
NHS South Tyneside	29	53.7	54
NHS South Sefton	39	52.7	74
NHS Hambleton, Richmondshire and Whitby	25	52.1	48
NHS Thurrock	25	52.1	48
NHS Blackburn with Darwen	24	51.1	47
NHS Hartlepool and Stockton-on-Tees	49	50.0	98
NHS Hull	45	50.0	90
NHS Leeds West	44	48.9	90
NHS Wakefield	54	48.7	111
...			
Lowest proportion of early stage disease	2	18.2	11

Source: National Cancer Registration and Analysis Service.[17] A total of 72 CCGs had stage data missing in more than 20 per cent of cases and have been excluded. This means a total of 137 out of 209 CCGs have been included in the analysis.

One-year survival

In its 2012 report on ovarian cancer, the National Cancer Registration and Analysis Service (then the National Cancer Intelligence Network) recognised that:

> **"Generally, poor one-year relative survival is considered to be related to delays in presentation and diagnosis."**
>
> (Overview of ovarian cancer in England: incidence, mortality and survival: 41)[18]

The one-year survival rate for women with ovarian cancer diagnosed in England currently stands at 76.5 per cent. While this has improved in recent years, this compares to a one-year survival rate of 96.3 per cent for breast cancer, 84.5 per cent for cervical cancer and 90.5 per cent for womb cancer.[19] Table 4 shows how one-year survival varies across CCGs.

One year survival ranges from over 90 per cent in some parts of England to under 60 per cent in others.

Table 4: Relative one-year survival by Clinical Commissioning Group (2008-2012)

Primary Care Trust	Relative one-year survival (per cent)
NHS Bradford City	96.4
NHS Haringey	87.7
NHS Kingston	87.3
NHS Southwark	87.3
NHS Bath and North East Somerset	86.4
NHS Wandsworth	86.4
NHS Richmond	86.1
NHS City and Hackney	85.6
NHS Leeds West	85.5
NHS Hammersmith and Fulham	84.8
...	
Lowest one-year survival	57.3

Source: National Cancer Registration and Analysis Service.[20]

Discussion

This report shows that there is significant regional variation across England. GPs in some parts of the country are 90 times more likely to order a CA125 blood test than others and while some are seeing non-obstetric ultrasounds carried out within days, others are waiting considerably longer. Stage at diagnosis varies widely, with some CCGs reporting over half of women diagnosed with stage I or II ovarian cancer, compared to as low as one in five in some parts of the country. One-year survival ranges from 90 per cent in some CCGs, to under 60 per cent in others.

Some of the variation can be explained by differences in demographics. For example, the number of CA125 blood tests ordered would be expected to be higher in an area with an older population and survival rates are not age standardised, so again, it is likely that areas with a larger older population will show poorer survival rates. In contrast, those with younger populations are likely to see more women diagnosed with borderline or germ cell ovarian cancer, which typically have higher survival rates.

The remaining variation may be explained by differences in three factors. The first is awareness of the symptoms. While awareness of ovarian cancer is increasing, still just one in five women are able to name bloating as a symptom of ovarian cancer.[21]

The second is GP knowledge. While former myths surrounding ovarian cancer are gradually being debunked, 44 per cent of GPs continue to believe that symptoms only present in the later stages of the disease and 41 per cent of women report having to visit their GP three times or more before being referred for diagnostic tests, well above the average for other cancers.[22]

The third is systems. This means GPs having direct access to diagnostic tests and for these tests to be carried out promptly. It is also the timely and accurate recording of data to enable pathways to be audited and improvements made.

The best-performing areas show what is possible and in the following pages are some of the steps that need to be taken if all areas are to reach the standard they set.

Recommendations

'Achieving world-class cancer outcomes: a strategy for England 2015-2020' calls for GPs to be given direct access to diagnostic tests and sets out new approaches to helping GPs diagnose cancer sooner, including trialling a referral pathway for vague symptoms. It also sets a requirement that CCGs diagnose or rule out cancer within four weeks of patients first presenting with symptoms.

The findings in this report show that significant improvements need to be made in the time taken to complete diagnostic tests if the new four week target is to be met for ovarian cancer.

1 By increasing the number of GPs trained in ovarian cancer, and NICE guidelines in particular, it should be possible to reduce the time between a woman first presenting with symptoms and being referred for diagnostic tests. Practice nurses are often the first contact point and as such should also be trained in the symptoms to look out for and the appropriate action to take.

2 Diagnosis could be sped up if the referral pathway was shortened. Scotland introduced guidance in 2013 which means that GPs can refer women for a CA125 blood test and non-obstetric ultrasound concurrently, rather than having to complete them consecutively as in England.[23]

3 As part of the cancer strategy NHS England has launched a cancer dashboard which currently provides key metrics for bowel, breast, lung and prostate cancer.[24] The dashboard is intended to drive the work of the newly formed Cancer Alliances which bring together service providers on a sub-regional basis.

The introduction of the cancer dashboard illustrates the importance of cancer data in driving improvements. The dashboard now needs extending to less common cancers such as ovarian.

4 To enable local areas to fully audit their own diagnostic pathway, it is important that they can access a breakdown of diagnostic data, including non-obstetric ultrasound data for suspected ovarian and other cancers.

Recommendations (continued)

5 Much of the data used in this study had incomplete or missing records. If there is to be the opportunity to learn from the best-performing areas and for others to identify where they must improve, it is essential that primary care health professionals are able to access accurate and reliable data on cancer testing, staging and survival in their area. Incentives should be introduced to ensure the accurate recording of data and penalties considered in areas where this persistently does not happen.

6 Work should be undertaken to help better understand what leads to differences between areas in diagnosing ovarian cancer. There may be learnings that can be taken from the best-performing parts of the country and applied to those areas where more could be done.

7 Finally, this report has not looked directly at issues of awareness, but ensuring women present early is an important factor in improving early diagnosis and the Be Clear on Cancer campaigns offer an opportunity to continue to raise awareness of the symptoms.

If we can see all parts of England meeting the standards of the best, then lives can be saved.

Appendix 1 - Methodology

CA125 testing
Data for CA125 testing is taken from the NHS Atlas.[25] It is collected once a year over a 23-day period then extrapolated to predict usage over the remainder of the year. Therefore this metric provides only the estimated annual rate of use for CA125 tests ordered by GPs per 1,000 practice population in 2012. It is broken down by PCT.[26]

Only aggregated data, not age-specific numbers are available. This means that only crude rates can be calculated rather than age-adjusted. Any comparison of the variation in the rate of CA125 testing may therefore not account for differences in the age structures of the populations.

The full data set can be found at: http://fingertips.phe.org.uk/profile/atlas-of-variation

Non-obstetric ultrasound
Data for the time taken for GP direct referrals for non-obstetric ultrasound to be carried out comes from the Diagnostic Imaging Dataset.[27] It covers April 2015-March 2016 and is broken down by CCG. Issues with data completeness mean it must be treated with caution.

The full data set can be found at: www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/diagnostic-imaging-dataset-2015-16-data

Stage at diagnosis
Stage data comes from the National Cancer Registration and Analysis Service.[28] It covers 2012-2014 inclusive and is broken down by CCG.

This does include borderline and germ cell tumour types which are typically diagnosed earlier and in younger women which may therefore skew the data in favour of areas with a proportionally younger population.

The full data set can be found at: www.ncin.org.uk/publications/survival_by_stage

One-year relative survival
One-year relative survival data comes from the National Cancer Registration and Analysis Service.[29] It covers 2008-2012 and is broken down by CCG.

Relative survival is defined as the observed survival rate in the cancer population divided by the expected survival rate of a similar cohort of people in the general population with respect to age, sex and year of observation. It is expressed as a percentage.[30] (Separate data provided for England-wide survival rates for ovarian and other cancers is age-standardised.)

These survival estimates are not age-standardised and therefore differences in survival when comparing across areas may be, in part, attributable to differences in the age profile of the cancer populations.

The full data set can be found at: www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/profiles

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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.

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