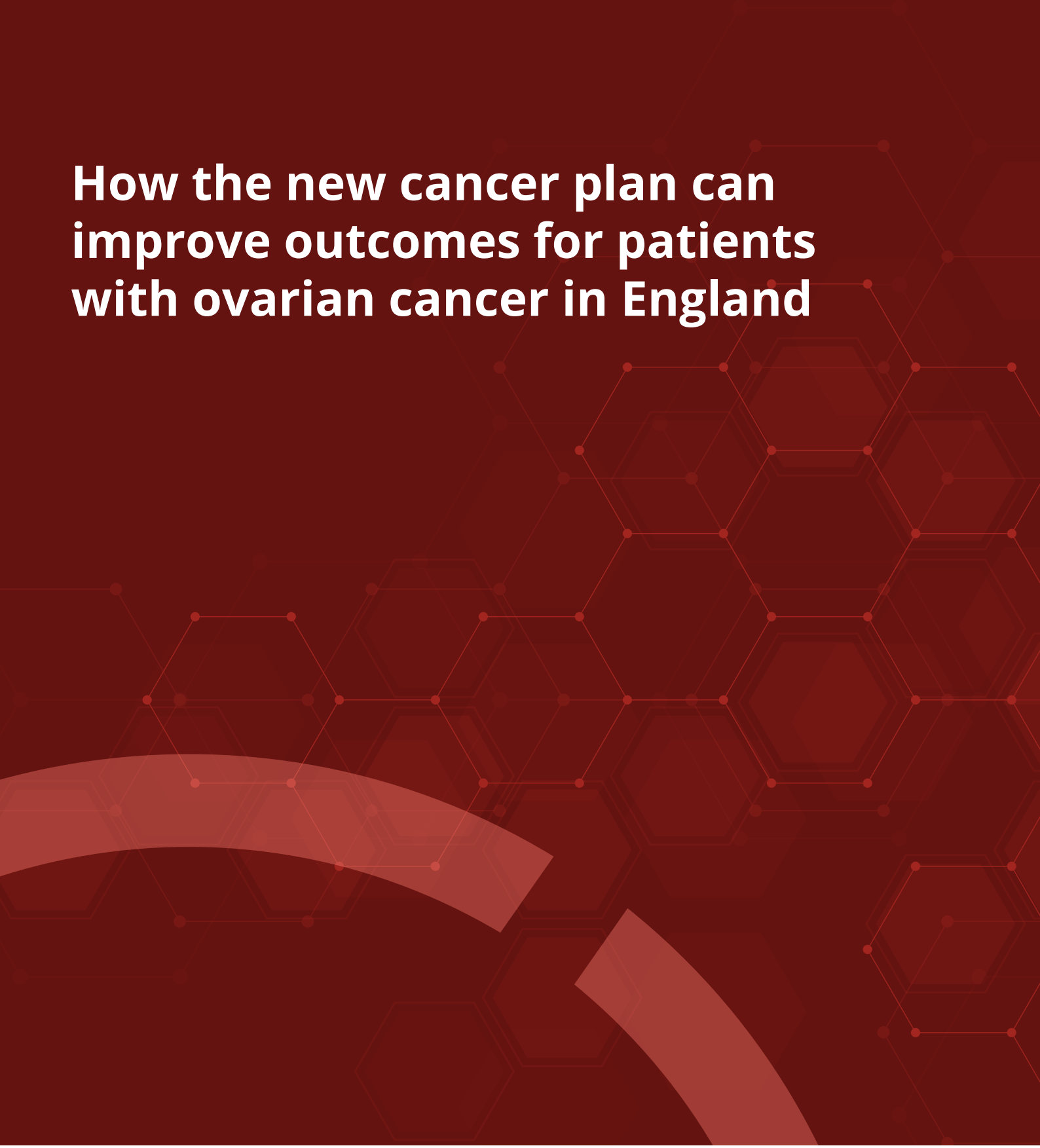
How the new cancer plan can improve outcomes for patients with ovarian cancer in England



FUTURE HEALTH

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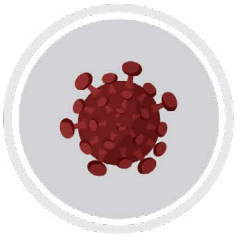
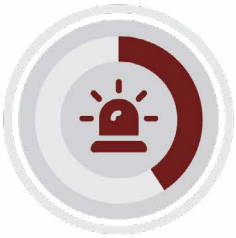


5,735

people diagnosed with ovarian cancer in 2021

71%

of cancers were diagnosed at either stage 3 or stage 4



41.4%

of those diagnosed had an emergency admission 28 days before diagnosis

1/4 women

diagnosed with stage 2 to 4 ovarian cancer did not have any treatment recorded

1/3 women

diagnosed with stage 2 to 4 ovarian cancer did not have any platinum based chemotherapy recorded

22%

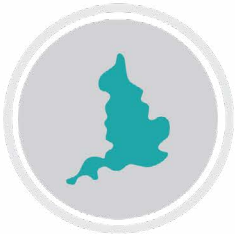
estimated range between ICBs recording patients with ovarian cancer admitted as an emergency 28 days prior to diagnosis with a similar range observed for one year survival rates

34%

estimated range recorded in rates of treatment at three months between ICBs

21%

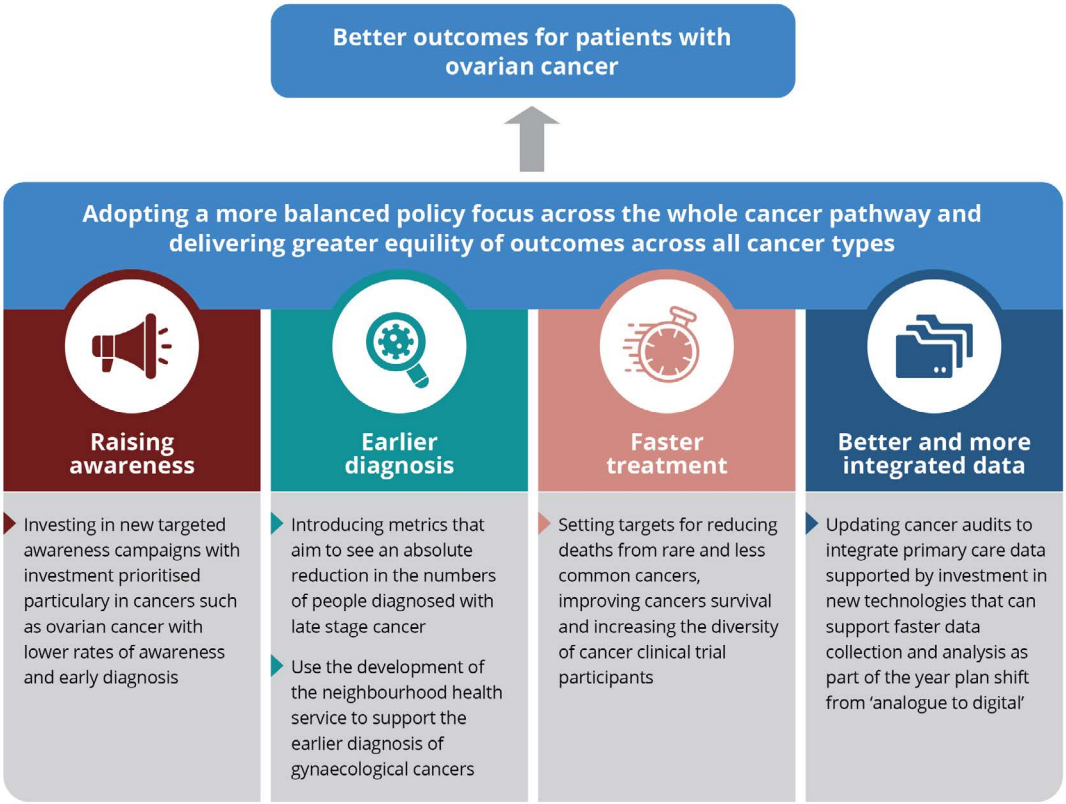
estimated range between ICBs for patients receiving treatment at nine months



Whilst many parts of the South West have high rates of treatment three months after a diagnosis, rates are much lower in parts of the North of England. Similarly treatment nine months after diagnosis is generally higher in the South West and London than it is in other regions

1 https://www.natcan.org.uk/reports/noca-state-of-the-nation-report-2024/

SUMMARY OF RECOMMENDATIONS



ABOUT THIS REPORT

This short report seeks to highlight differences in the regional impact of ovarian cancer. The data are taken from the National Ovarian Cancer Audit.[2]

With the forthcoming publication of a new cancer plan there is an opportunity for policymakers to take new action to increase awareness of ovarian cancer, improve diagnosis rates and ensure that barriers to treatment are removed. In particular the research argues that the new cancer plan will need to adopt a more balanced policy focus across the whole cancer pathway to be successful and should also have a stated aim of delivering greater equity of outcomes between different types of cancers.

The report was commissioned and funded by AbbVie. Future Health has independent editorial control of the report.

Future Health would like to thank the following who agreed to short interviews as part of this research: Victoria Clare (Ovacome), Catherine Hart and Rachel Downing (Target Ovarian Cancer), Sasha Daly (Cancer52) and Jason Pawluk and Hazel Rodger (West Yorkshire Cancer Alliance). Future Health would also like to thank all those ovarian cancer patients who kindly spoke to us for this research. All views in this report are those of Future Health only and should be attributed as such.

ABOUT FUTURE HEALTH

Future Health is a public policy research centre focused on creating healthier, wealthier people, communities and nations.

Future Health publishes regular research papers across its three policy research programmes of health prevention, health technology and the links between improvements in health and economic growth.

You can find out more about our research here: https://www.futurehealth-research.com/

2 https://www.natcan.org.uk/wp-content/uploads/2024/09/NOCA-State-of-the-Nation-Report-2024-v1.0_12.09.24.pdf

INTRODUCTION

Across the UK there are 41,000 women living with ovarian cancer and over 6,000 women each year in England are diagnosed with the condition.[3] [4] Over 4,000 women lose their lives each year.[5]

Ovarian cancer is the sixth most common cause of cancer related death in the UK amongst women.[6] There are a number of different types of ovarian cancer depending on the type of cell they originate from.[7]

Ovarian cancer is often diagnosed at an advanced stage due to limited awareness of symptoms and a lack of effective early screening methods. The main symptoms of ovarian cancer are:

- Persistent bloating
- Feeling full quickly and/or loss of appetite
- Pelvic or abdominal pain
- Urinary symptoms (needing to wee more urgently or more often than usual)

Other symptoms include changes in bowel habit, extreme fatigue and unexplained weight loss.[8]

Late-stage detection leads to later treatment and poorer survival rates than many other cancers. The UK has recorded some of the poorest ovarian cancer outcomes in Europe.[9] NHS data show that the estimated five year survival rate from ovarian cancer in England is 45%. This is the sixth poorest outcome out of 25 cancers measured. It is less than half the rate of cancer of the testis and melanoma that have the highest estimated five year survival rates.[10]

However if diagnosed early, 9 in 10 women diagnosed with ovarian cancer will survive.[11]

3 https://targetovariancancer.org.uk/about-us/media-centre/key-facts-and-figures

4 https://targetovariancancer.org.uk/sites/default/files/2025-06/National%20Cancer%20Plan%20final%20submission%202025.pdf

5 https://targetovariancancer.org.uk/about-us/media-centre/key-facts-and-figures

6 https://pmc.ncbi.nlm.nih.gov/articles/PMC9472236/

7 https://targetovariancancer.org.uk/about-ovarian-cancer/what-ovarian-cancer/types-ovarian-cancer

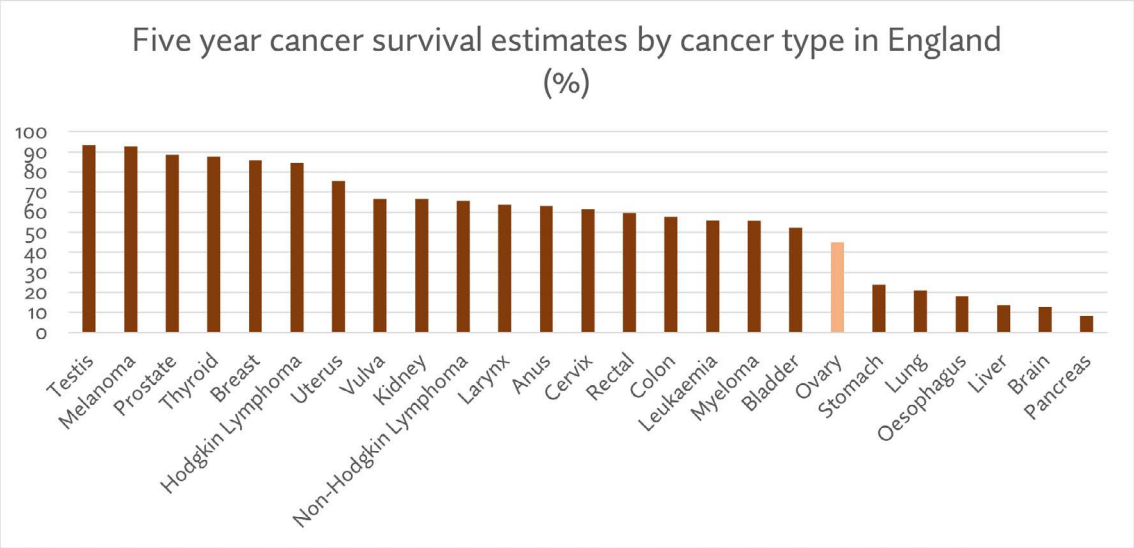
8 https://www.cancerresearchuk.org/about-cancer/ovariancancer/symptoms

9 https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(13)70546-1/abstract

10 https://digital.nhs.uk/data-and-information/publications/statistical/cancer-survival-in-england/cancers-diagnosed-2016-to-2020-followed-up-to-2021

11 https://targetovariancancer.org.uk/about-us/media-centre/key-facts-and-figures

Figure 1: Estimated five year survival rates by cancer type in England (2016-2020)[12]

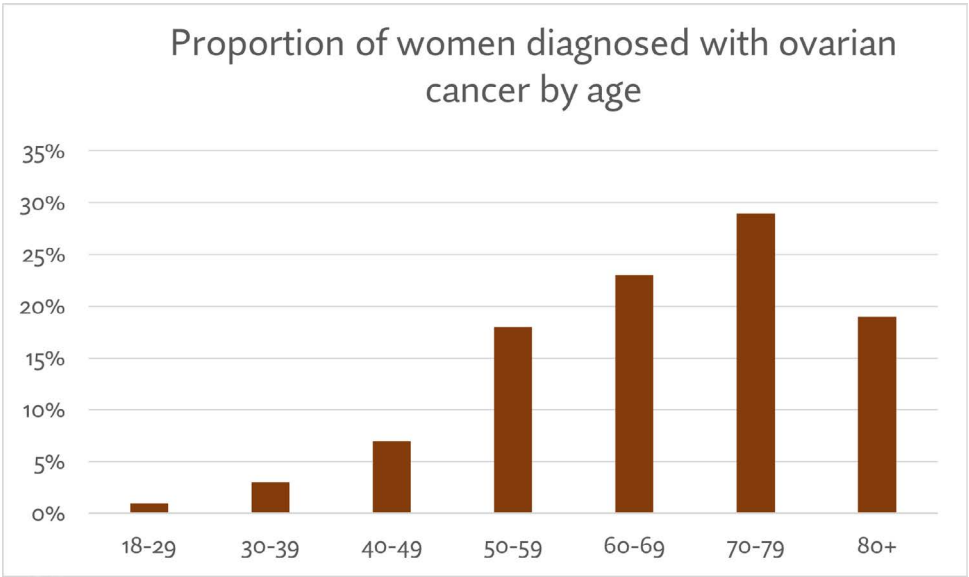


Ovarian cancer across England – mapping the current impact

In September 2024 the National Cancer Audit Collaborating Centre published the National Ovarian Cancer Audit State of the Nation Report. The report captured the care received by women with ovarian cancer in England in 2021 and Wales in 2022.[13]

The audit recorded 5,735 cases of ovarian cancer in England. The mean age of diagnosis was 66.6, with the numbers diagnosed increasing with age up until age 79.

Figure 2: Proportion of women diagnosed with ovarian cancer by age[14]

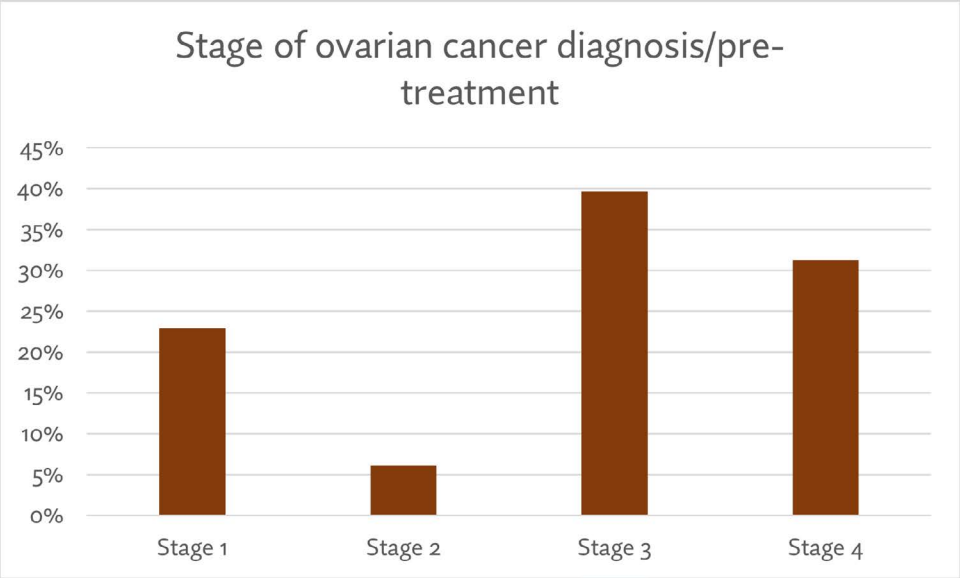


12 https://www.nuffieldtrust.org.uk/resource/cancer-survival-rates#:~:text=The%20cancers%20with%20the%20lowest,and%20prostate%20cancer%20(88.5%25)

13 https://www.natcan.org.uk/wp-content/uploads/2024/09/NOCA-State-of-the-Nation-Report-2024-v1.0_12.09.24.pdf

14 https://www.natcan.org.uk/wp-content/uploads/2024/09/NOCA-State-of-the-Nation-Report2024-v1.0_12.09.24.pdf

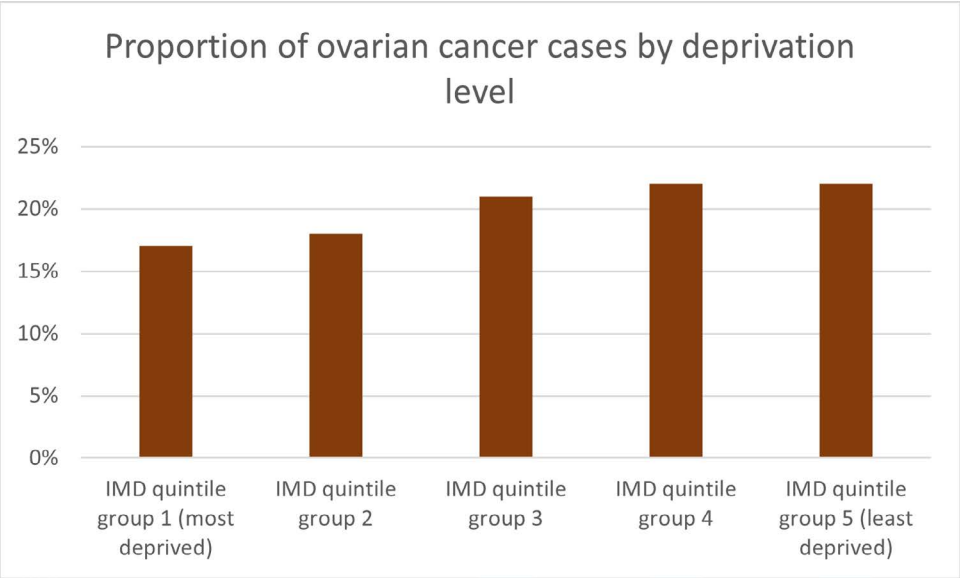
Figure 3: Stage of ovarian cancer diagnosis/pre treatment[15]



The audit reveals significant disparities in diagnosis timing, with the highest percentage of patients being diagnosed at Stage 3, accounting for approximately 40% of cases. Stage 4 follows closely behind at around 30% – highlighting that a substantial number of cases are detected at advanced stages. In contrast, only about 20% of patients are diagnosed at Stage 1, while Stage 2 has the lowest representation at roughly 5%.

Notably, approximately 25% of patients are categorised in the audit as "unstaged," highlighting a lack of complete diagnostic data.

Figure 4: Proportion of ovarian cancer cases by deprivation level[16]



15 https://www.natcan.org.uk/wp-content/uploads/2024/09/NOCA-State-of-the-Nation-Report2024-v1.0_12.09.24.pdf

16 https://www.natcan.org.uk/wp-content/uploads/2024/09/NOCA-State-of-the-Nation-Report2024-v1.0_12.09.24.pdf

The data indicate relatively consistent proportions of ovarian cancer cases across all quintile groups, with some slight variations. Quintile groups 3, 4, and 5 (where deprivation is lower) have the highest proportions of diagnoses, hovering above 20% each. Quintile groups 1 and 2 (where deprivation is highest) have slightly lower proportions, recording rates just under 20%.

OVARIAN CANCER OUTCOMES AND QUALITY OF CARE

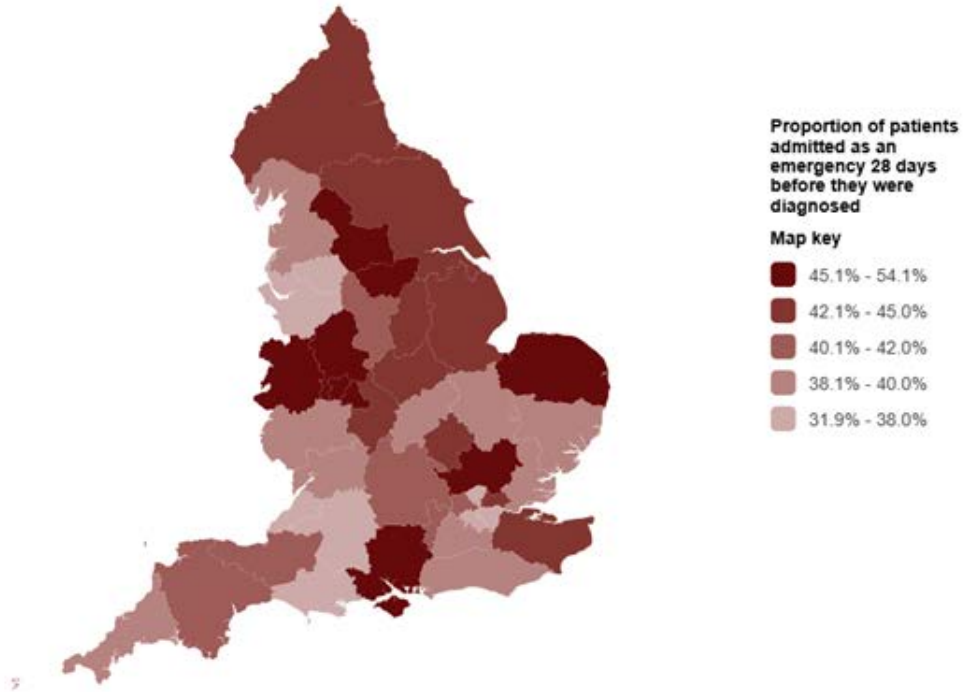
The Audit tracks a number of data points seeking to assess the quality of ovarian cancer care across NHS Trusts in England. These include:

- Whether patients were admitted as an emergency 28 days before they were diagnosed
- One year survival rates
- Treatment rates

It is important to note that each NHS Trust sees a different number of ovarian cancer patients and there are real differences in the number of patients included in the audit by each Trust. For example Royal United Hospitals Bath NHS Foundation Trust recorded 47 ovarian cancer patients through the audit, while Manchester NHS Foundation Trust recorded 342. This is a seven fold variation in patient numbers.

The data from the Audit is captured by Integrated Gynaecological Cancer System. In order to map the data across England Future Health converted this data into estimated data by Integrated Care Board.[17]

Figure 5: Estimated proportion of women with ovarian cancer who had an emergency admission 28 days prior to diagnosis by Integrated Care Board



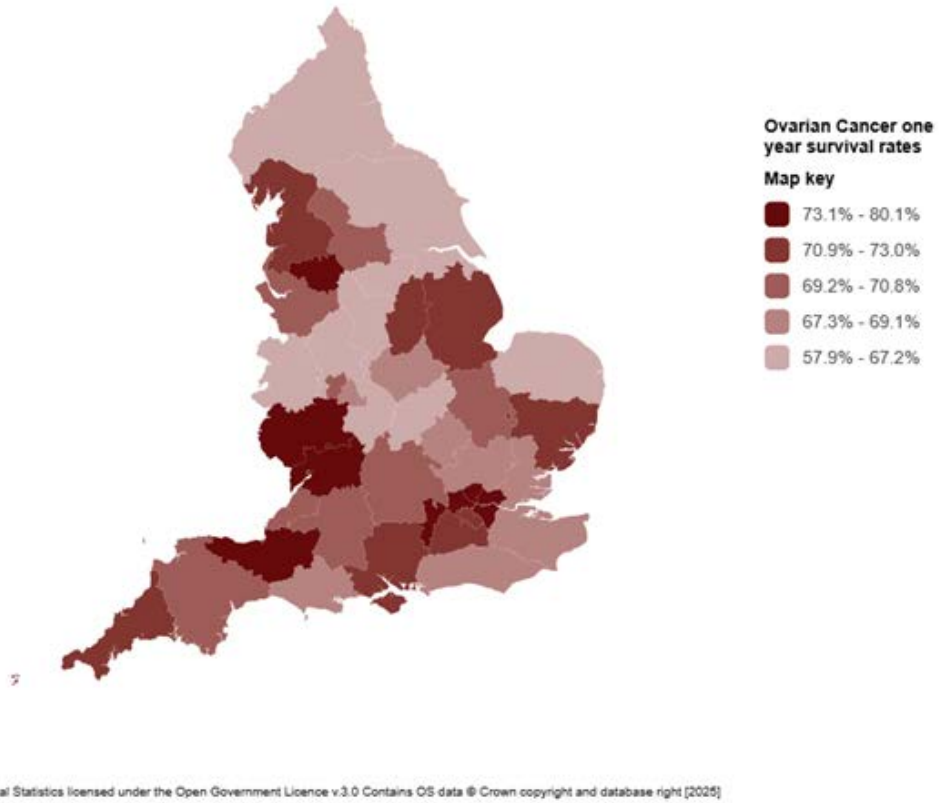
Source: Office for National Statistics licensed under the Open Government Licence v.3.0 Contains OS data © Crown copyright and database right [2025]

17 The methodology in Annex A provides further information on how the data was converted. All data here are presented as estimates and should be treated as such

The data reveal a notable variation of 22% in the proportion of patients admitted as an emergency 28 days prior to diagnosis. 13 ICBs recorded the proportion of women admitted as an emergency 28 days of diagnosis below 40%. NHS Dorset ICB has the lowest emergency admission rate 28 days prior to diagnosis at 32%, followed by NHS Greater Manchester ICB at 34%. Several other ICBs are also within the mid-30% range, particularly in the South West and London.

By contrast, the NHS Staffordshire and Stoke-On-Trent ICB and NHS Shropshire, Telford and Wrekin ICB record the highest proportion of women admitted as an emergency 28 days prior to diagnosis – 54%. 11 ICBs have rates of 45% or higher, including a number of ICBs in the West Midlands and Yorkshire.

Figure 6: Estimated one year survival rates for ovarian cancer by Integrated Care Board

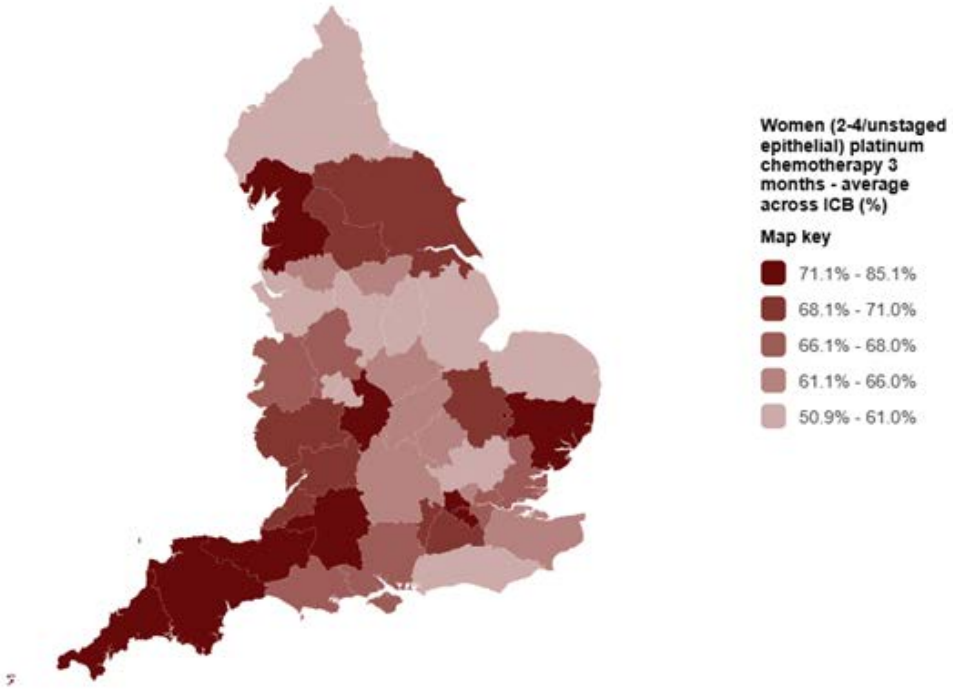


There is a 22% variation between the ICB with the highest one year survival rate and the ICB with the lowest one year survival rate.

NHS South Yorkshire ICB records the lowest one year survival rate at 58%, over 5% below the next lowest value of 63.1% in NHS Derby and Derbyshire ICB. Several other ICBs fall within the low-to-mid 60% range. 13 ICBs record rates of 67.5% including a number in the Midlands, North West and North East.

NHS North East London ICB has the highest one year survival rate at 80.0%. Eight ICBs record a one year survival rate of 74% or higher. This includes four London ICBs, NHS Greater Manchester ICB, NHS Gloucestershire ICB, NHS Herefordshire and Worcestershire ICB and NHS Somerset ICB.

Figure 7: Estimated platinum based chemotherapy rates by Integrated Care Board for ovarian cancer patients with stage 2 to 4, or unstaged cancer three months after diagnosis

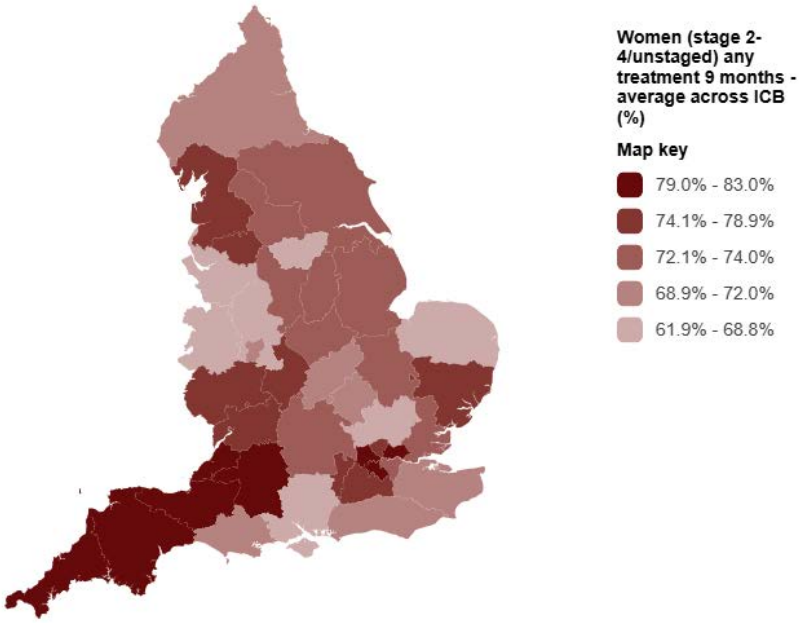


There is a 34% difference between ICBs in the estimated treatment rate for women with platinum chemotherapy three months after diagnosis.

The lowest rate is observed in NHS Norfolk and Waveney ICB at 51%, which is well below the next lowest figure of 58% in both NHS Cheshire and Merseyside and NHS Hertfordshire and West Essex ICBs. Several other ICBs fall within the low-to-mid 60% range.

At the upper end, NHS Somerset ICB demonstrates the highest treatment rate at 85%. 14 ICBs including five from the South West record treatment rates of 70% or higher.

Figure 8: Estimated treatment rates for ovarian cancer patients with stage 2 to 4, or unstaged diagnoses by Integrated Care Board at nine months



The audit reveals a considerable spread in treatment rates across ICBs, ranging from 62% to 83%. This 21% difference underscores potential inequities in cancer care across regions, with some areas achieving significantly higher treatment engagement than others.

The lowest rate is observed in NHS Norfolk and Waveney ICB at 62%, followed by NHS Cheshire and Merseyside ICB at 65.6%. Several others, including NHS Shropshire, Telford and Wrekin and NHS Staffordshire and Stoke-On-Trent ICBs, are within the mid-60% range.

NHS South West London ICB records the highest treatment rate at 83%. Eight ICBs record rates of 79% or higher. Five are in the South West of England (NHS Devon ICB, NHS Cornwall and the Isles of Scilly ICB, NHS Bath And North East Somerset, Swindon and Wiltshire ICB, NHS Somerset ICB, NHS Bristol, North Somerset and South Gloucestershire ICB) and three are in London (NHS South West London ICB, NHS North West London ICB and NHS North East London).

Summary

The audit reveals quite significant variations in the quality of care for patients with ovarian cancer.

There is a 22% range between areas recording patients admitted as an emergency 28 days prior to diagnosis with a similar range observed for one year survival rates. It is important to treat the data with an element of caution as patient access to health services was disrupted by the pandemic, but understanding such variation in more detail feels important.

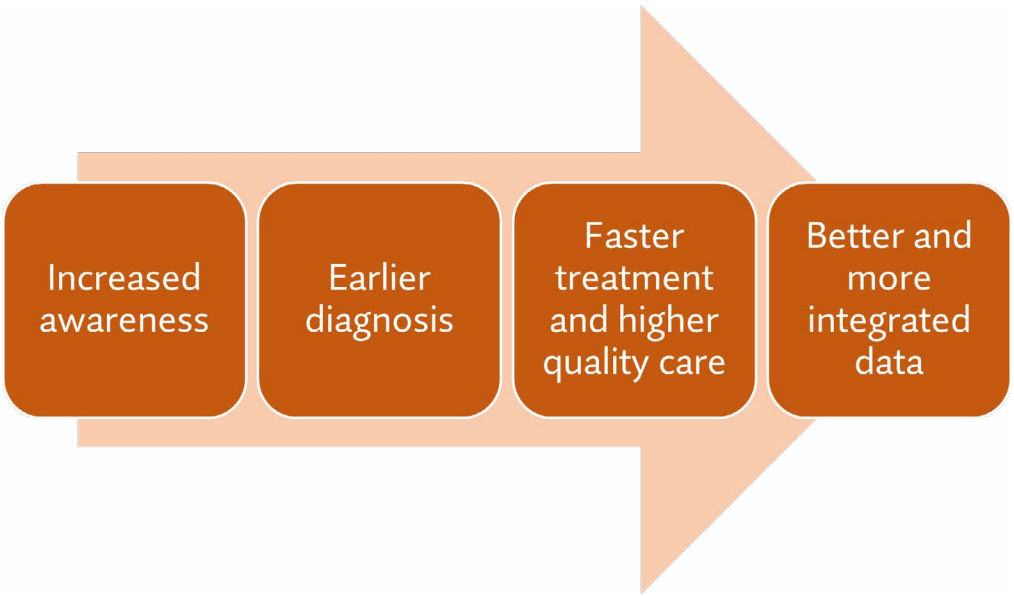
There are also wide regional ranges and inequalities in treatment rates between ICBs. Whilst many parts of the South West have high rates of treatment three months after a diagnosis, rates are much lower in parts of the North of England. Similarly treatment nine months after diagnosis is generally higher in the South West and London than it is in other regions.

OPPORTUNITIES TO IMPROVE OUTCOMES FOR PATIENTS WITH OVARIAN CANCER

The Government is planning reforms to the health system with an aim of building 'an NHS fit for the future: that is there when people need it; with fewer lives lost to the biggest killers; in a fairer Britain, where everyone lives well for longer.'[18] Improving cancer outcomes – including those with ovarian cancer – should be one of the measures by which such plans are judged.

The findings from the audit point to four main opportunities for improving ovarian cancer outcomes in England.

Figure 9: Policy opportunities for improving outcomes for patients with ovarian cancer'



Improving awareness of ovarian cancer symptoms

The audit highlights that 4 in 10 women in England with ovarian cancer were admitted as an emergency 28 days prior to diagnosis; with 'women admitted as an emergency having worse cancer outcomes than women diagnosed via nonemergency routes.'[19]

It adds that this highlights the need 'to increase symptom awareness amongst patients and primary care professionals.'[20] A challenge with ovarian cancer is that the symptoms can be vague, non-specific and similar to other conditions. Ovarian cancer is often misdiagnosed as irritable bowel syndrome (IBS).[21]

18 https://www.gov.uk/missions/nhs

19 https://www.natcan.org.uk/wp-content/uploads/2024/09/NOCA-State-of-the-Nation-Report-2024-v1.0_12.09.24.pdf

20 https://www.natcan.org.uk/wp-content/uploads/2024/09/NOCA-State-of-the-Nation-Report-2024-v1.0_12.09.24.pdf

21 https://eveappeal.org.uk/information-and-advice/gynaecological-cancers/ovarian-cancer/#:~:text=What%20are%20the%20signs%20and,Changes%20in%20bowel%20habits

There are opportunities for greater proactivity from the NHS in communicating the symptoms and risks of ovarian cancer to particular groups of patients. Such a 'making every contact count' approach could include women invited for breast or cervical screening tests; where there is an opportunity for visits to be used to raise awareness of ovarian cancer risk. The new NHS ten year plan commits to an expansion of cancer screening.[22]

There is also an opportunity to address misinformation about ovarian cancer – surveys have shown that 40% of women mistakenly believe that a cervical screen can detect ovarian cancer.[23] [24]

Patient case study: Samixa

In the last 13 years, I have seen a lot more work done in raising awareness of ovarian cancer which has resulted in a slight improvement in diagnosis rates. In addition, initiatives like 'Survivors Teaching Students' through Ovacome are used to educate the medical community to help improve the rate of early diagnosis. I think more work is now needed on making sure that all patients diagnosed with ovarian cancer have a holistic needs assessment which can help to formulate a personalised care plan for the patient. There are lots of opportunities to do this, with the different mix of clinicians, health care professionals and social prescribers we have now. I think this would make a big difference to patient outcomes and their quality of life.[25]

Any public campaigns will though need to be properly targeted so they are focused on those communities most at risk and where there are existing health inequalities. Ovacome has worked with a wide variety of community groups to reach people with culturally appropriate symptom awareness messaging, information, and support on ovarian cancer.[26]

As an example, the charity has worked on a campaign with OUTpatients to raise ovarian cancer awareness in trans and non-binary communities – who face higher rates of healthcare discrimination.[27] [28] Local health services are vital partners in tailoring and adapting national campaigns – which only engage with certain groups of

22 https://assets.publishing.service.gov.uk/media/6866387fe6557c544c74db7a/fit-for-the-future-10-year-health-plan-for-england.pdf

23 https://targetovariancancer.org.uk/sites/default/files/2024-09/Three%20Targets%20agenda%20-%20Target%20Ovarian%20Cancer.pdf

24 NHS England has recently announced a policy change to cervical screening that will see invitations sent out every five years rather than every three: https://www.england.nhs.uk/cancer/early-diagnosis/screening-and-earlier-diagnosis/#:~:text=Cervical%20screening,-The%20NHS%20cervical&text=Routine%20screening%20is%20offered%20every,ask%20Eve%20nurse%20information%20service

25 Interview with researcher

26 Researcher interview with Ovacome

27 https://www.ovacome.org.uk/ovacome-and-outpatients-awareness-campaign

28 https://www.bma.org.uk/advice-and-support/equality-and-diversity-guidance/lgbtplus-equality-in-medicine/inclusive-care-of-trans-and-non-binary-patients#:~:text=40%25%20of%20trans%20respondents%20who,12%20months%20preceding%20the%20survey.&text=18%25%20had%20avoided%20treatment%20for%20fear%20of%20a%20negative%20reaction

patients – for local communities. There is uncertainty about how such engagement will be done and by whom as a further round of NHS restructuring takes place.[29]

The Government's cancer plan should be used to invest in new targeted awareness campaigns with investment prioritised particularly in cancers such as ovarian cancer with lower rates of awareness and higher rates of late diagnosis.

Digital channels also present relatively low cost opportunities for increasing awareness. Ovacome uses Whatsapp to distribute awareness videos to its advocates who can then share them through their networks. Further updates to the NHS App as part of the ten year NHS plan are expected and can be used to provide targeted and accredited information on ovarian cancer risks to relevant patient populations.

Given the challenges around symptoms, supporting healthcare professional awareness through education is particularly important. The number of cases means that it is expected that GPs will see one ovarian cancer case every five years.[30] Research by Hamilton et al has also highlighted that the positive predictive value of the main symptoms - abdominal pain, bloating, loss of appetite, urinary frequency, post-menopausal bleeding, rectal bleeding – is less than 2.5%.[31]

Target Ovarian Cancer runs a series of modules for health professionals on symptoms, diagnostic tests and treatment options.[32]

West Yorkshire Cancer Alliance has sought to bring primary and secondary care colleagues together in a collaborative way to explore patient case studies and learnings to inform future service pathways and care delivery.[33] Whilst there is a need to raise awareness amongst GPs, it is important to ensure that the symptoms of ovarian cancer are understood right across the primary care workforce as patients may present in a variety of different ways – for example to a physio with abdominal pain.

Recommendation: ***The Government's cancer plan should be used to invest in new targeted awareness campaigns with investment prioritised particularly in cancers such as ovarian cancer with lower rates of awareness and higher rates of late diagnosis***

Earlier diagnosis

The audit shows that 71% of ovarian cancers in England are diagnosed at a late stage (stages three and four).[34] According to NHS cancer registration statistics only pancreatic and oesophageal cancers have higher rates of late diagnosis than this figure.[35]

29 https://www.hsj.co.uk/policy-and-regulation/icbs-ordered-to-cut-costs-by-50/7038846.article

30 https://pmc.ncbi.nlm.nih.gov/articles/PMC9472236/#r32

31 https://pmc.ncbi.nlm.nih.gov/articles/PMC2731836/

32 https://targetovariancancer.org.uk/health-professionals/update-your-knowledge/ovarian-cancer-treatment

33 Feedback from expert interview

34 https://www.natcan.org.uk/wp-content/uploads/2024/09/NOCA-State-of-the-Nation-Report-2024-v1.0_12.09.24.pdf

35 https://digital.nhs.uk/data-and-information/publications/statistical/cancer-registration-statistics/england-2020/cancer-incidence-by-stage

Part of the challenge is the misrepresentation of ovarian cancer as a 'silent killer' in the media, where symptoms only present at a late stage. This can create the incorrect view that an earlier diagnosis is not possible.[36]

Patient case study: Linda

'What does a rare cancer diagnosis feel like? Isolating? Confusing? Both of these and more! In January 2007, I was diagnosed with Granulosa Cell Tumour (GCT), a rare type of ovarian cancer – accounting for 2-5% of all ovarian cancers. I was given no information at the time, just that it could possibly reappear, but that was unlikely; if it did, it would be 20-30 years' hence, and require a simple operation. I wasn't told it was an ovarian cancer, my staging, or whether I should see an oncologist. Of course I went home and googled GCT, but everything referred to cancer, recurrences, medications, even chemotherapy, so I couldn't align this with what I had been told, believing my diagnosis was something different. But of course, it wasn't!'[37]

Under the current system women presenting with symptoms to a GP should be referred for a CA125 blood test, and if that is higher than expected an ultrasound can subsequently be ordered.[38] There are delays both in accessing tests and with GPs then receiving the results – 40% of GPs have reported waiting 15 days or more for an ultrasound.[39] Evidence from GPs also shows that patients request CA125 tests far less frequently than other tests – such as the prostate-specific antigen testing (PSA).[40]

It is important to note that the CA125 blood test only picks up 50% of early stage disease.[41] To address both the delays in tests and the limitations of current diagnostic tools, Target Ovarian Cancer is calling for the CA125 and ultrasound tests to be undertaken at the same time.[42]

Given some of the issues about identifying ovarian cancer symptoms, the emergence of non specific symptom pathways and Community Diagnostic Centres creates opportunities to identify patients with ovarian cancer earlier – although there remain clear service capacity challenges in meeting demand.[43] The previous Government's women's health strategy sought to expand women's health hubs that could help improve access to services for women and join-up care around patient needs.

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36 https://targetovariancancer.org.uk/sites/default/files/2021-08/Identifying%20and%20breaking%20down%20barriers%20to%20early%20diagnosis%20of%20ovarian%20cancer.pdf

37 Interview with report author

38 https://targetovariancancer.org.uk/sites/default/files/2024-09/Three%20Targets%20agenda%20-%20Target%20Ovarian%20Cancer.pdf

39 https://targetovariancancer.org.uk/sites/default/files/2024-09/Three%20Targets%20agenda%20-%20Target%20Ovarian%20Cancer.pdf

40 https://targetovariancancer.org.uk/sites/default/files/2021-08/Identifying%20and%20breaking%20down%20barriers%20to%20early%20diagnosis%20of%20ovarian%20cancer.pdf

41 https://www.swbh.nhs.uk/news/2m-boost-for-study-to-detect-early-stage-ovarian-cancer/#:~:text=The%20project%20involves%20Sandwell%20and,experiencing%20symptoms%20of%20ovarian%20cancer

42 https://targetovariancancer.org.uk/sites/default/files/2024-09/Three%20Targets%20agenda%20-%20Target%20Ovarian%20Cancer.pdf

43 https://www.rcr.ac.uk/news-policy/policy-reports-initiatives/representing-your-voice-in-uk-parliaments/cdcs-unveiled-challenges-and-triumphs/

To date they have not been utilised as part of the diagnostic pathway for ovarian cancer.[44] The development of a neighbourhood health service as part of the Government's ten year NHS plan is a potential enabler for better joining up health for women and improving the early diagnosis of gynaecological cancers.[45] [46]

New diagnostic tools for ovarian cancer are also being trialled. Sandwell and West Birmingham NHS Trust and Walsall Healthcare NHS Trust have paired up with primary care provider Modality and the University of Birmingham, to offer a blood test called ROMA to patients experiencing symptoms of ovarian cancer. A previous study found that the ROMA test had detected up to 20% more early-stage cancers than the current test. The trial called SONATA (transforming ovarian cancer diagnostic pathways), is due to run until late 2025 and is designed to build further evidence of its effectiveness.[47]

With 20% of ovarian cancers being hereditary there are also opportunities emerging for genetic testing to help identify women at higher risk.[48]

Given the current high numbers of people diagnosed with late stage ovarian cancer and the subsequent impact on patient outcomes, metrics should be introduced through the ten year NHS plan and cancer plan that aim to see an absolute reduction in the numbers of people diagnosed with late stage cancer.[49]

Recommendation: *Metrics should be introduced through the ten year NHS plan and cancer plan that aim to see an absolute reduction in the numbers of people diagnosed with late stage cancer*

Recommendation: *The development of a neighbourhood health service as part of the ten year NHS plan should support the expansion of women's health hubs and set out how it will support the earlier diagnosis of gynaecological cancers*

Faster access to treatment and higher quality care

One out of four women recorded with an ovarian cancer diagnosis of stage 2-4 through the audit were not receiving any treatment.[50]

There is also evidence that older women receive less anti-cancer treatment than younger women.[51] [52]

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44 https://targetovariancancer.org.uk/sites/default/files/2025-06/Response%20to%20NHS%20Long%20Term%20Plan.pdf

45 https://assets.publishing.service.gov.uk/media/6866387fe6557c544c74db7a/fit-for-the-future-10-year-health-plan-for-england.pdf

46 https://targetovariancancer.org.uk/sites/default/files/2025-06/Response%20to%20NHS%20Long%20Term%20Plan.pdf

47 https://www.swbh.nhs.uk/news/2m-boost-for-study-to-detect-early-stage-ovarian-cancer/#:~:text=The%20project%20involves%20Sandwell%20and,experiencing%20symptoms%20of%20ovarian%20cancer

48 https://ocrahope.org/resources-support/free-genetic-testing-program/

49 https://www.datocms-assets.com/111063/1745573222-incisive-health-getting-upstream-report.pdf

50 https://www.natcan.org.uk/wp-content/uploads/2024/09/NOCA-State-of-the-Nation-Report-2024-v1.0_12.09.24.pdf

51 https://pmc.ncbi.nlm.nih.gov/articles/PMC8001330/

52 https://targetovariancancer.org.uk/about-ovarian-cancer/clinical-trials/fair-o-study-looking-how-deliver-better-care-older-women

More treatments are becoming available for patients but there remain concerns about the capacity in the system to deliver them. Studies have shown that receiving treatment at a major specialist centre can improve survival by 45%.[53]

Waiting lists for treatment within the broader gynaecological pathway are high and there are system wide issues on access to diagnostics such as CT scanners.[54]

There is a 15% shortfall in clinical oncologists which is forecast to rise to 25% by 2027.[55] High vacancy rates have been identified in gynaecology specifically.[56] Pathology services are also facing significant demand pressures.[57] [58]

Patient case study: Linda

'When I got my cancer diagnosis I felt completely on my own. I only found out about cancer nurse specialists five years into my cancer journey. I now run a Facebook group for women with GCT. One of the issues that is regularly raised is just how difficult it is to find out the best person to speak to – whether it is about appointments, results or treatment options to get the reassurance and help that they need. Cancer nurse specialists are so important for communicating with and supporting patients through their care. They are a godsend.'[59]

To be a success the Government's cancer plan will need to have a broader approach than in the past – where there has often been a strong policy focus on diagnosis and waiting times for treatment. Whilst clearly important – the Government's call for evidence on the plan signalled a welcome broader approach to policy development across the cancer pathway.[60] Cancer52 has called for the new cancer plan to set a target to reduce the number of deaths from rare and less common cancers.[61] Cancer Research UK has also called for a national commitment to reduce the cancer mortality rate by 15% by 2040 – preventing 20,000 cancer deaths every year and making the UK's cancer survival one of the best in the world.[62]

53 https://pubmed.ncbi.nlm.nih.gov/27401967/#:~:text=Overall%20survival%20was%2C%20however%2C%2045,that%20achieved%20in%20international%20centres

54 https://www.bmj.com/content/387/bmj.q2552.full

55 https://www.rcr.ac.uk/news-policy/latest-updates/cancer-leaders-sound-alarm-at-worsening-delays-for-patients/#:~:text=We%20face%20a%20ticking%20timebomb,%2C%20up%20from%2015%25%20today.&text=Hospitals%20are%20increasingly%20relying%20on,largely%20by%20our%20ageing%20population

56 https://www.rcr.ac.uk/media/iq4c1ivv/clinical_oncology_census_report_2019.pdf

57 https://www.rcpath.org/discover-pathology/public-affairs/the-pathology-workforce.html#:~:text=Pathologists%20are%20facing%20great%20pressures,year%20on%20year%20since%202007

58 https://pmc.ncbi.nlm.nih.gov/articles/PMC9345238/

59 Interview with research author

60 https://www.gov.uk/government/calls-for-evidence/shaping-the-national-cancer-plan/shaping-the-national-cancer-plan#:~:text=The%2010%20Year%20Health%20Plan%20will%20set%20out%20how%20the,effective%20to%20reduce%20cancer%20mortality

61 https://www.cancer52.org.uk/single-post/cancer52-launches-manifesto-for-rare-and-less-common-cancers

62 https://www.cancerresearchuk.org/sites/default/files/cruk_manifesto.pdf

Efforts to improve the clinical trials environment following the O'Shaughnessy review should help improve access to experimental treatments for patients, and the Cancer Drugs Fund has also enabled patients with less common and rare cancers to access innovative cancer medicines.[63]

However there remain concerns about access to clinical trials for those with rare and less common cancers. A survey by Cancer52 found 'over four-fifths (82%) of patients with a rare or less common cancer were not offered an opportunity to be part of a clinical trial. Over two-thirds (68%) said the main barrier was not knowing about any trials, indicating a need for better communication about research opportunities.'[64] Issues have also been highlighted regarding the lack of diversity of participants in ovarian cancer clinical trials.[65] Further efforts are needed here as part of wider health system energy channelled into addressing health inequalities.

Recommendation: *The Government should adopt a more balanced policy focus across the whole cancer pathway in the forthcoming cancer plan*

Recommendation: *The forthcoming cancer plan should set targets for reducing deaths from rare and less common cancers, improving cancer survival and increasing the diversity of cancer clinical trial participants*

Better and more integrated data

The State of the Nation Ovarian Cancer Audit is a very helpful tool for understanding the quality of care and outcomes for patients with ovarian cancer across England.

However it is not complete. The audit focuses on secondary care activity and does not cover primary care. For ovarian cancer, the fragmented data collection across the NHS is an inhibitor to identifying patients at risk. For example the lack of join-up of family health data means that hereditary risk is difficult to identify and makes more proactive case finding challenging.

Given the Government's priorities for three shifts in the ten year NHS plan – moving care from hospital to community, from treatment to prevention and from analogue to digital – evolving the audit so that primary care data is fully integrated should be the ambition. This will help identify challenges and issues right across the ovarian cancer pathway and help support more effective system-level population-wide responses.[66]

63 https://www.gov.uk/government/publications/commercial-clinical-trials-in-the-uk-the-lord-oshaughnessy-review/commercial-clinical-trials-in-the-uk-the-lord-oshaughnessy-review-final-report

64 https://e2236186-a9de-45db-b8f6-3f2d6db40cb4.usrfiles.com/ugd/e22361_9bcebf3bb6724611b7dd4ac8fa465164.pdf

65 https://qmro.qmul.ac.uk/xmlui/bitstream/handle/123456789/104025/Ethnicity%20and%20Socioeconomic%20Disparities%20in%20Clinical%20Trial%20Participation%20for%20Ovarian%20Cancer%20A%20Retrospective%20Observational%20Stu.pdf?sequence=2&isAllowed=y#:~:text=Simple%20Summary%3A%20This%20study%20on,and%20from%20less%20deprived%20areas

66 https://www.sciencedirect.com/science/article/pii/S1877782124001826

In addition and as part of wider reforms to healthcare data through the ten year NHS plan, efforts – supported by new technologies and faster systems – should be made to accelerate the data collection and publication of cancer audits such as the Ovarian Cancer State of the Nation.[67]

Recommendation: *Updates to cancer audits such as the ovarian cancer audit should work on integrating primary care data and be supported by investment in new technologies that can support faster data collection and analysis as part of the ten year NHS plan shift from 'analogue' to digital'*

67 Please also see: https://www.futurehealth-research.com/site/wp-content/uploads/2021/12/Cancer-Data-Report-2021-210125.pdf

CONCLUSION AND SUMMARY OF RECOMMENDATIONS

The forthcoming cancer plan as well as the three shifts in the ten year NHS plan present opportunities to make new progress in raising awareness, increasing earlier diagnosis rates and improving access to treatment for patients with ovarian cancer.

To do this the plan will need to focus on delivering greater equity of outcomes between rare and less common cancers, such as ovarian cancer and more common cancer types. The following recommendations should help support this:

- Adopting a more balanced policy focus in the new cancer plan across the whole cancer pathway
- Investing in new targeted awareness campaigns with investment prioritised particularly in cancers such as ovarian cancer with lower rates of awareness and early diagnosis
- Introducing metrics that aim to see an absolute reduction in the numbers of people diagnosed with late stage cancer
- The development of a neighbourhood health service as part of the ten year NHS plan should support the expansion of women's health hubs and set out how it will support the earlier diagnosis of gynaecological cancers
- Setting targets for reducing deaths from rare and less common cancers, improving survival and increasing the diversity of cancer clinical trial participants
- Updating cancer audits to integrate primary care data supported by investment in new technologies that can support faster data collection and analysis as part of the ten year NHS plan shift from 'analogue' to digital'

ANNEX A: METHODOLOGY

As part of the research it was felt helpful to map the variation in outcomes identified through the National Ovarian Cancer Audit State of the Nation report. To create the maps, data from the audit was adapted to Integrated Care Board geographies.

The mapping analysis took four data points across Integrated gynaecological cancer systems (see chapter 3) from the latest National Ovarian Cancer Audit State of the Nation report.[68]

Future Health then used the methodology supplement to the report to identify the NHS Trusts within each Integrated gynaecological cancer system.[69]

NHS Trust level percentage data for each indicator was then assigned to an ICB in England using data from NHS England.[70]

The percentages from each NHS Trust within each ICB for each indicator were then averaged to estimate an ICB level figure for each of the four indicators.

All ICB level figures are estimates, are presented as such in this report and should be treated as such.

68 https://www.natcan.org.uk/reports/noca-state-of-the-nation-report-2024/

69 https://www.natcan.org.uk/wp-content/uploads/2024/09/NOCA-SotN-Methodology-v1.0_12.09.24.pdf

70 https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2023/02/Trust-ICB-Attribution-File.xls

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