Public Health England

BRITISH GYNAECOLOGICAL CANCER SOCIETY

Ovarian Cancer Audit Feasibility Pilot

Disease Profile in England: Incidence, mortality, stage and survival for ovary, fallopian tube and primary peritoneal carcinomas

January 2020

ovarian cancer action

TARGET OVARIAN CANCER

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Data for this report is based on patient-level information collected by the NHS, as part of the care and support of cancer patients. The data is collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England (PHE).

Contents

Introduction

The Ovarian Cancer Audit Feasibility Pilot is a collaboration between the gynaecological oncology clinical community, the charity sector and Public Health England to perform meaningful analysis of routinely collected data for the purposes of improving treatment and outcomes for women diagnosed with ovarian cancer in England. The Ovarian Cancer Audit Feasibility Pilot is jointly funded by the British Gynaecological Cancer Society, Target Ovarian Cancer and Ovarian Cancer Action and is being delivered by analysts at the National Cancer Registration and Analysis Service (NCRAS), part of Public Health England. The pilot will run for 2 years and will publish a range of data outputs on ovarian cancer throughout that time, including a final report on the audit and its findings, bringing all the analysis into one place. Outputs can be found on the project website.

This document constitutes the first report of a series of analyses throughout the 2-year project. It provides a detailed insight into the status of this disease in England at the commencement of the project, including details of disease incidence, mortality and survival. In keeping with international ovarian cancer analyses, we have included cases of ovary, fallopian tube and primary peritoneal carcinomas within our definition of “ovarian cancer” in these analyses, and for the survival statistics we have excluded ovarian tumours of borderline malignant potential. We have also provided survival statistics with borderline tumours included for historical comparison purposes.

The analyses are achieved by linking databases which capture clinical data on cancer and its treatment in routine day-to-day practice in NHS hospitals in England. The Cancer Outcomes and Services Dataset (COSD) captures details of every cancer diagnosed in NHS organisations, including pathology details and a set of important clinical parameters such as disease stage and WHO performance status. Details of chemotherapy treatments are captured in the Systemic Anti-Cancer Therapy (SACT) dataset, and extensive data relating to hospital treatments including surgical procedures and patient comorbidities can be derived from Hospital Episode Statistics (HES) datasets. The Cancer Waiting Times (CWT) data set captures details of the pathways leading to the diagnosis of cancers in England, and Office for National Statistics data enables insight into the deaths of cancer patients, either from cancer or other causes.

The analysts in the NCRAS, in collaboration with representatives of the 3 funding charities, have identified cases of ovary, fallopian tube and primary peritoneal carcinomas and by linkage to these additional datasets have produced the following analyses to profile the disease in England. This is a new, streamlined approach to clinical audit. Rather than collect fresh information, it uses data already collected by medical teams and engages with clinicians through existing clinical networks. The quality and subsequent success of the project is therefore dependent on the level of

completeness and accuracy of the data captured in these datasets, and extensive work is being done with the provider NHS Trusts and multidisciplinary teams (MDTs) to optimise the quality of data. The latest completeness information is available to providers via the CancerStats portal.

This initial disease profile report is intended to enable comparison with international jurisdictions, and identification of regional variation which should lead to improvements in clinical practice and outcomes in due course. Data presented in this report are also available in the accompanying Excel workbook.

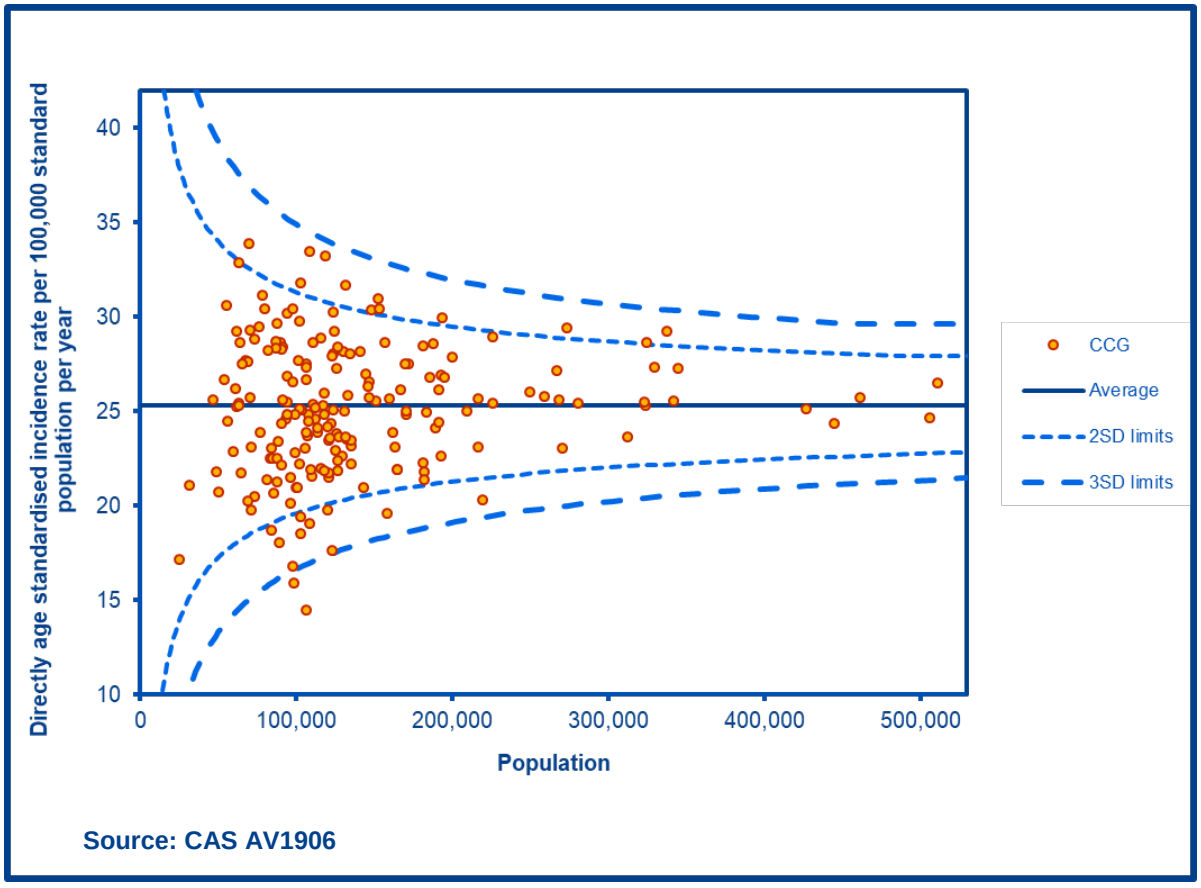
Incidence

Incidence of ovary, fallopian tube and primary peritoneal carcinomas, 2015 to 2017

There were 6,902 diagnoses of ovary, fallopian tube and primary peritoneal carcinomas per year on average in England in 2015 to 2017 (20,707 over the 3-year period), including tumours with borderline malignant potential. The overall crude incidence rate for the period was 24.7 cases per 100,000 person-years. See Appendix 1 for cohort definition in terms of ICD-10 and ICD-O-2 codes.

Age standardisation was used to enable comparison of Clinical Commissioning Groups (CCGs) with different age profiles. Age standardised incidence rates in the 195 CCGs ranged from 14.5 to 33.9 cases per 100,000 person-years.

Incidence data by CCG, Sustainability and Transformation Partnership (STP) and Cancer Alliance and for all of England are available in the accompanying Excel workbook.



CORRECTED Figure 1. Ovary, fallopian tube and primary peritoneal carcinomas: directly age standardised incidence rates by CCG, 2015 to 2017

Each point on the funnel plot represents a geographical area (in this case, CCG). The population of each CCG is presented on the horizontal axis and the (age standardised) incidence rate of ovary, fallopian tube and primary peritoneal carcinomas is shown on the vertical axis. Some random variation in rates between areas is expected, but the estimate of the rate of these cancers is likely to be more precise for a larger area than for a smaller one. This precision level is represented by the 'funnel' dashed lines. Points that lie outside of the dashed lines indicate that such variation may not be explained solely by randomness but may be due to real differences in incidence between areas.

Age standardisation was used to enable comparison of Cancer Alliances with different age profiles. Age standardised incidence rates in the 19 Cancer Alliances ranged from 21.8 to 27.5 cases per 100,000 person-years.

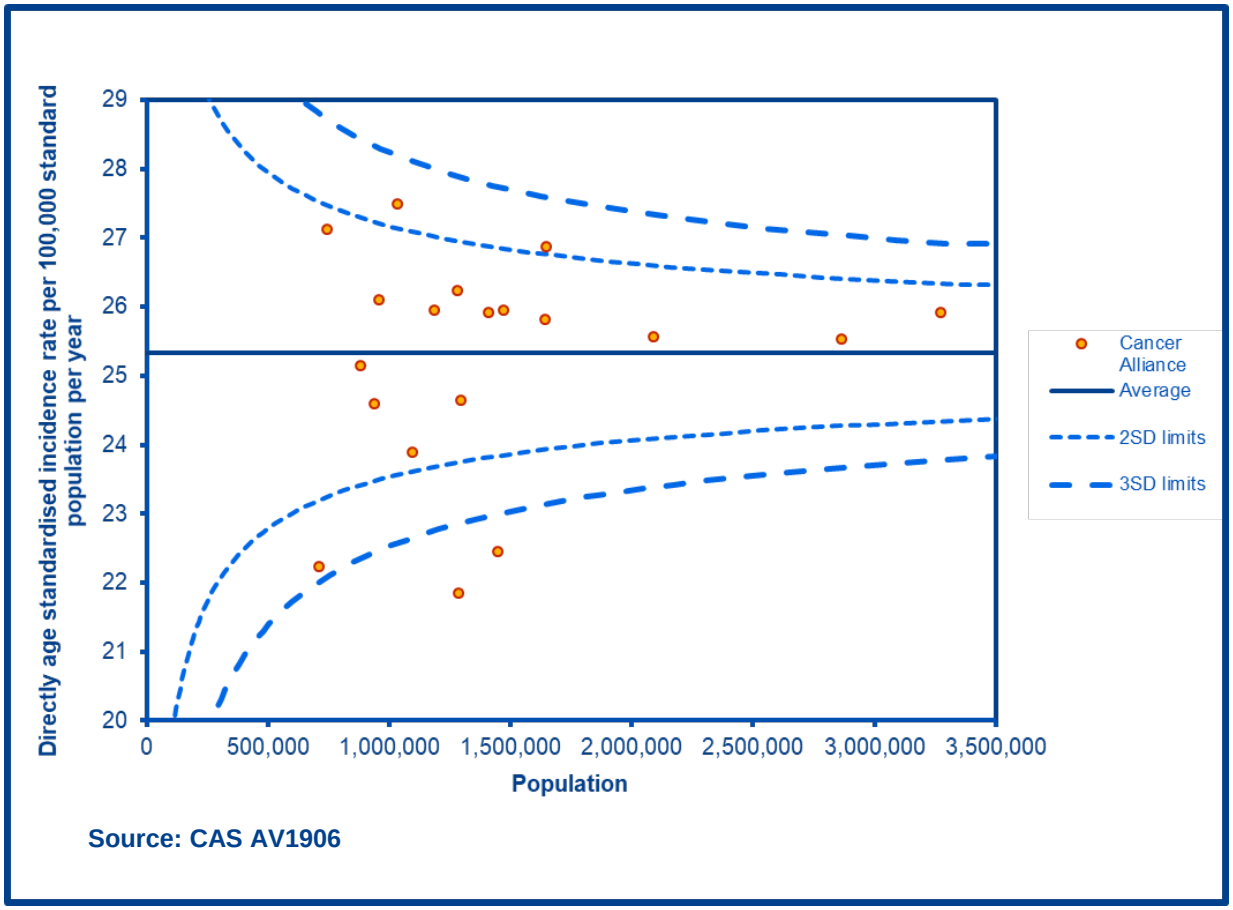


Figure 2. Ovary, fallopian tube and primary peritoneal carcinomas: directly age standardised incidence rates by Cancer Alliance, 2015 to 2017

These funnel plots show unexpected variation in incidence of ovary, fallopian tube and primary peritoneal carcinomas among local geographies (identified by Clinical Commissioning Groups) and regional geographies (identified by Cancer Alliances). Previously it has been thought that regional variation in incidence may reflect differences in the methods and conventions used for distinguishing between ovary, fallopian tube and primary peritoneal carcinomas at diagnosis. However the new

methodology, which includes all of these diseases in the analysis, avoids this as a confounding factor. Age standardisation removes the impact of differences in population age profile on incidence rates, but variation in ethnicity and regional variation in other disease risk factors such as use of hormonal contraception could impact on these data.

Incidence of ovary, fallopian tube and primary peritoneal carcinomas, 2001 to 2017

The crude incidence rate of ovary, fallopian tube and primary peritoneal carcinomas in England has fluctuated at around 25 cases per 100,000 women between 2001 and 2017. The crude rate in 2001 was 25.4 cases per 100,000 women and in 2017 it was observed to be 24.3 cases per 100,000 women.

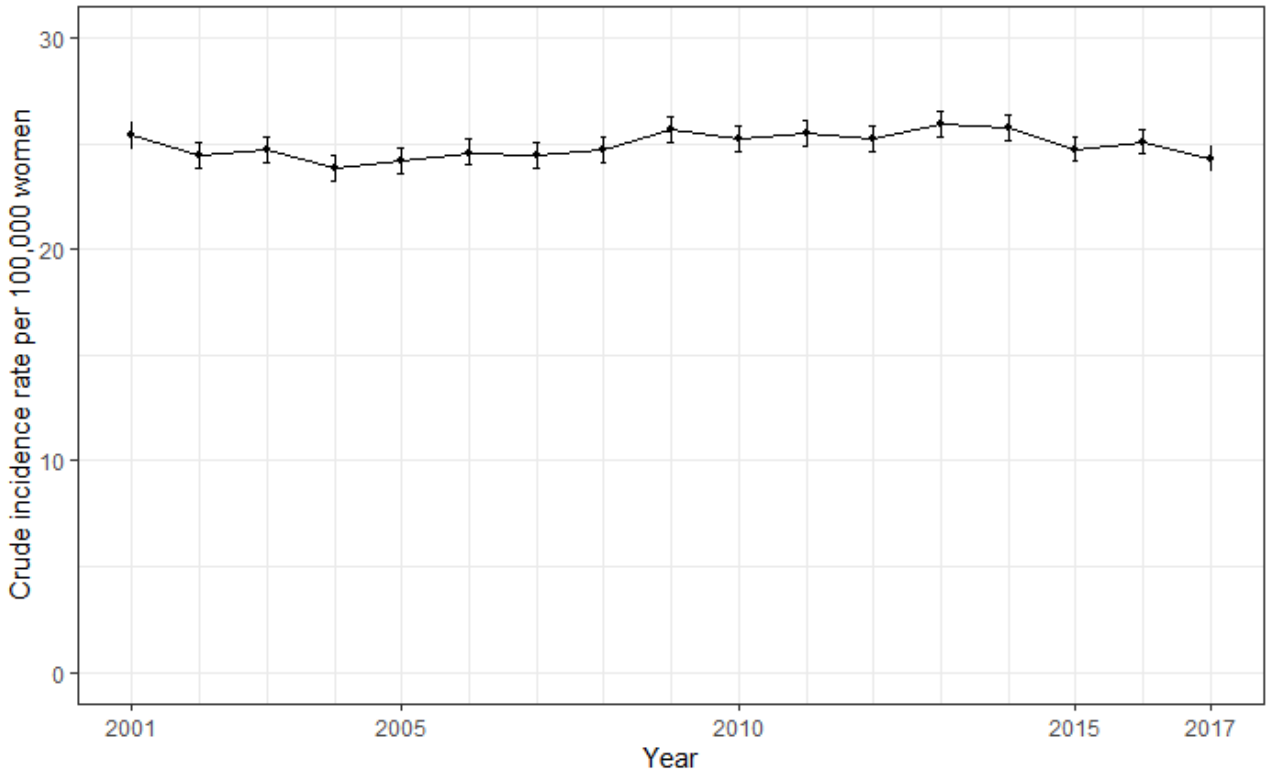


Figure 3. Crude rate of ovary, fallopian tube and primary peritoneal carcinomas in England, 2001 to 2017 (Source: CAS AV1907 and ONS2017)

There is no significant trend in ovary, fallopian tube and primary peritoneal carcinomas incidence over the period 2001 – 2017.

Mortality

Mortality from ovarian cancer, 2015 to 2017

There were 3,509 deaths from ovarian cancer (C56-C57 in ICD-10) per year on average in 2015 to 2017 (10,528 over the 3-year period). The overall crude mortality rate was 12.6 deaths per 100,000 person-years. See Appendix 1 for cohort definition in terms of ICD-10 codes.

Age standardisation was used to enable comparison of CCGs with different age profiles. Age standardised mortality rates in the 195 CCGs ranged from 6.2 to 21.3 per 100,000 person-years. Two CCGs with low rates of ovarian cancer mortality have been omitted from the funnel plot as their counts of ovarian cancer mortality were too small to calculate age standardised rates.

Mortality data by CCG, STP and Cancer Alliance and for all of England are available in the accompanying Excel workbook.

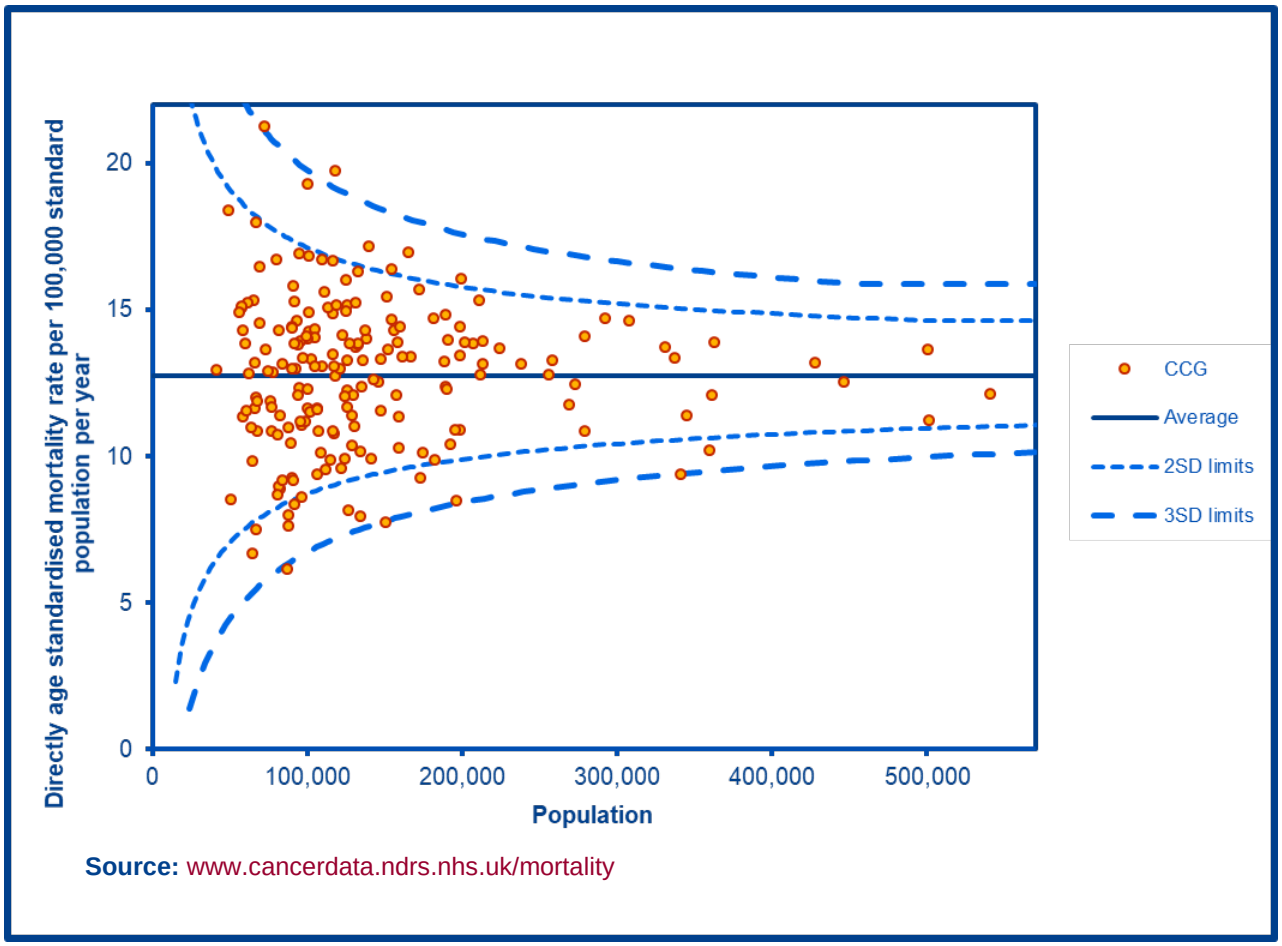


Figure 4. Ovarian cancer: directly age standardised mortality rates by CCG, 2015 to 2017

Mortality rates from cancer are driven by many factors including incidence rates (how many patients get cancer), stage (how advanced their disease is at the time of diagnosis), comorbidities (what other conditions they suffer from) and treatments

received (and whether these prolong the patient's life). Mortality rates do not specify how long patients survive after diagnosis or treatment.

Stage

The stage of a cancer describes the size of the tumour and how far it has grown and spread; a larger number indicates a later stage and more extensive disease. Disease staging is fundamental to the management of cancer cases, and all diagnosed cases of ovary, fallopian tube and primary peritoneal carcinomas should be staged by the MDT managing the case. When the patient is too unwell at the time of diagnosis (due to very advanced disease or comorbidities) to undergo full investigations and / or surgery, it may not be possible for the MDT to record stage data.

Stage presented in this report is 'registry stage': the stage at diagnosis of the tumour. Registry stage is primarily FIGO stage provided to the registry by the diagnosing trust via the MDT; the registry will review this stage and combine with information from pathology reports and clinical investigations to record the most accurate stage at diagnosis possible. If insufficient data to confirm a 'registry stage' is available to the registry (from all sources) the tumour is considered to have 'Stage unknown' or 'Stage not recorded' in this report.

For more detailed information on staging, see Appendix 2. The cohort used includes all ovary, fallopian tube and primary peritoneal carcinomas, including borderline tumours. See Appendix 1 for the cohort definition in terms of ICD-10 and ICD-O-2 codes.

Stage data by CCG, STP and Cancer Alliance and for all of England are available in the accompanying Excel workbook.

Stage at diagnosis of ovary, fallopian tube and primary peritoneal carcinomas in England, 2015 to 2017

	Stage 1	Stage 2	Stage 3	Stage 4	Stage Unknown
England	27.9%	5.4%	31.8%	18.4%	16.5%

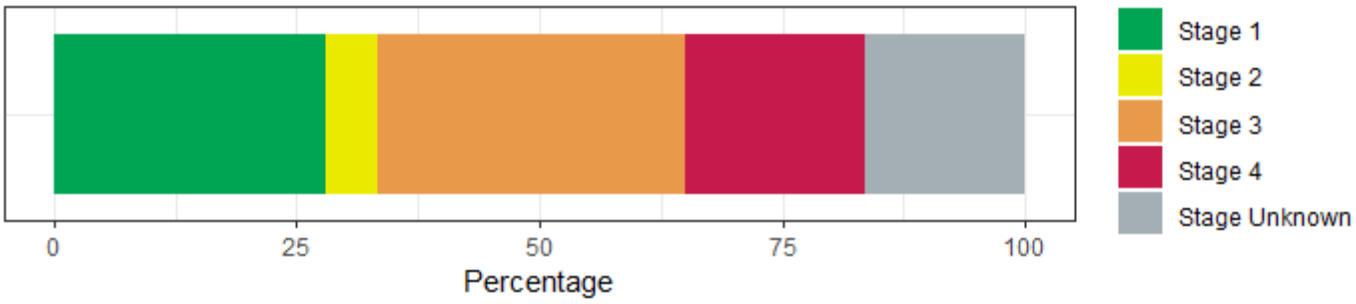


Figure 5. Stage at diagnosis of ovary, fallopian tube and primary peritoneal carcinomas in England, 2015 to 2017 (Source: CAS AV1906)

Variation in stage at diagnosis of ovary, fallopian tube and primary peritoneal carcinomas by CCG, 2015 to 2017

The proportion of tumours diagnosed at Stage 1 ranged from 10.0% to 47.9% among the 195 CCGs.

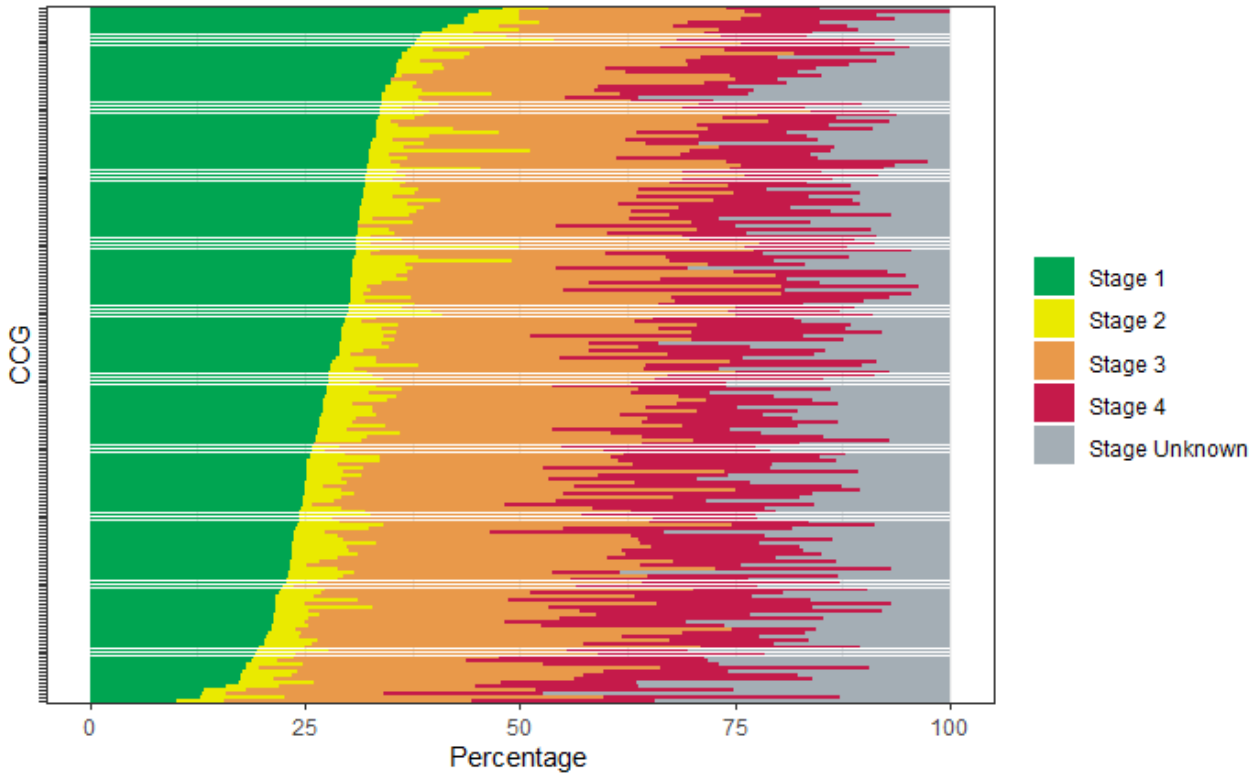


Figure 6. Stage at diagnosis of ovary, fallopian tube and primary peritoneal carcinomas by CCG, 2015 to 2017 (Source: CAS AV1906)

There are substantial differences in the stage profile across different geographies. Regional variation in stage data should be interpreted with care. Differences may be driven by how the data has been recorded or by real variation in the profile of cases diagnosed in different regions. Potential explanations for any real variation in stage profiles include differences in diagnostic pathways between regions, varying patterns of the time taken for patients to seek to consult their GP after first experiencing symptoms, inequality in ease of access in primary care to consult a GP for assessment of symptoms, variations in referral practices amongst GPs, and regional differences in primary care access to investigations such as ultrasound.

Variation in proportion of ovary, fallopian tube and primary peritoneal carcinomas with stage recorded by CCG, 2015 to 2017

The proportion of tumours registered with registry stage recorded ranged from 100% to 52.6% amongst the CCGs.

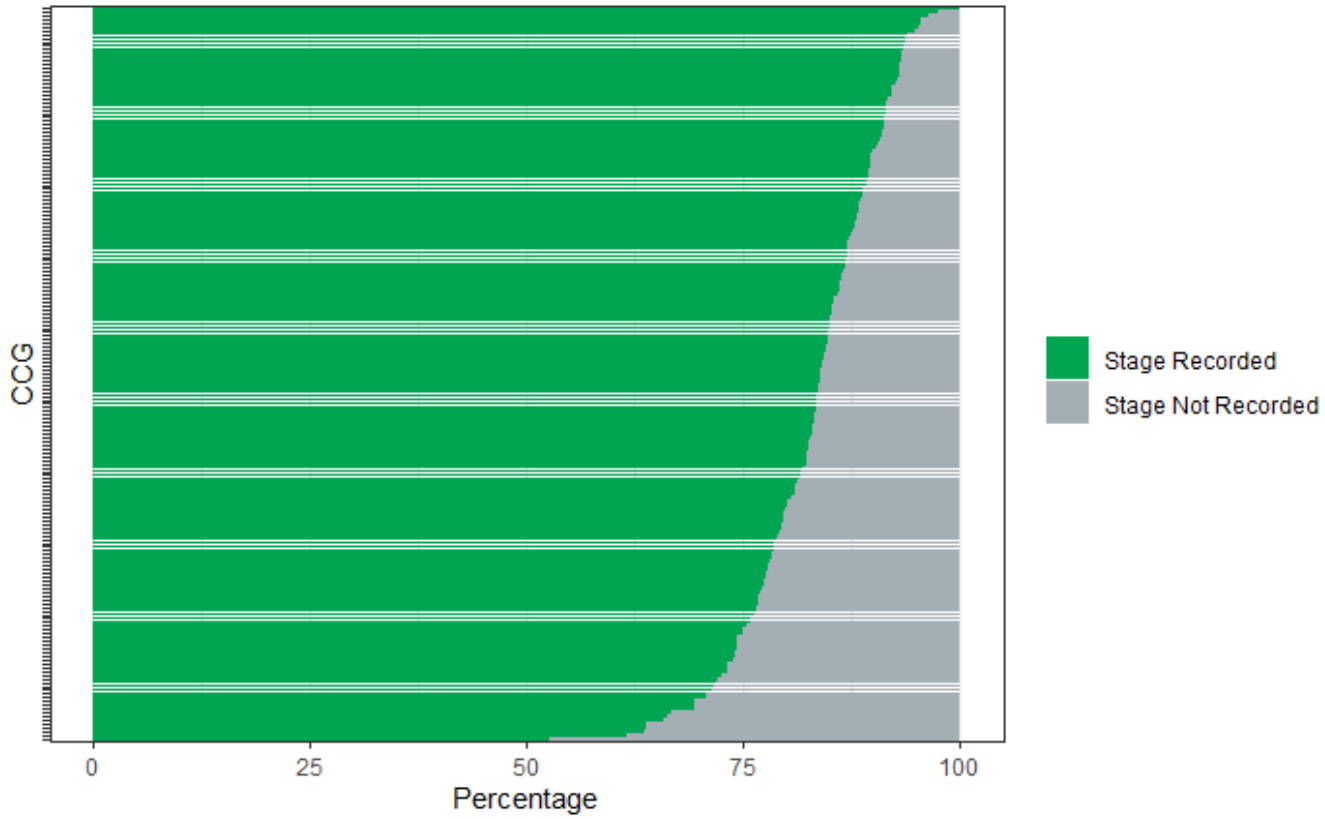


Figure 7. Ovary, fallopian tube and primary peritoneal carcinomas with stage recorded by CCG, 2015 to 2017 (Source: CAS AV1906)

A total of 17% of cases considered in this report do not have registry stage recorded; this varies geographically with up to 48% of cases in particular CCGs having unknown stage.

The Ovarian Cancer Audit Feasibility Pilot reports the completeness of stage data in the datasets uploaded to the cancer registry by MDTs on a routine basis, with the aim of improving the completeness of this data where this is clinically appropriate. This information is available to NHS staff via the CancerStats website.

Variation in proportion of ovary, fallopian tube and primary peritoneal carcinomas diagnosed at early stage vs late stage amongst tumours with stage recorded by CCG, 2015 to 2017.

The proportion of tumours diagnosed at early stage (stages 1 and 2) ranged from 62.9% to 21.8% amongst the CCGs. The definition of “early stage” as stage 1 or 2 and “late stage” as stage 3 or 4 is the same as the definition in the NHS Long Term Plan which sets an ambition for 75% of cancers to be diagnosed at stage 1 or 2 by 2028.

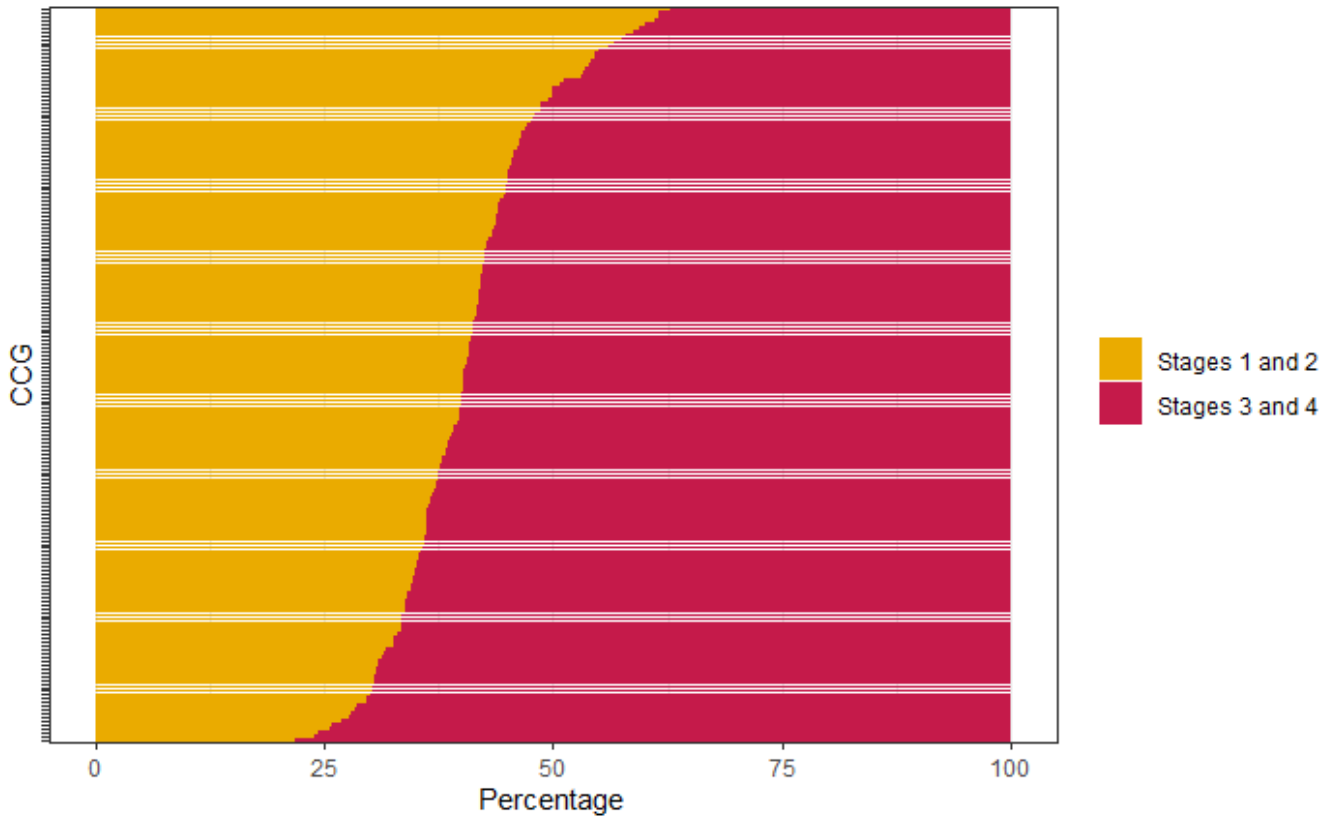


Figure 8. Ovary, fallopian tube and primary peritoneal carcinomas diagnosed at early or late stage by CCG, 2015 to 2017 (Source: CAS AV1906)

There are substantial differences in the early stage profile across different geographies. Potential explanations for this variation include differences in stage completeness, as well as referral and diagnostic pathways. This project’s future work analysing Routes to Diagnosis and treatments for ovarian cancer in England may help to disentangle the causes and consequences of variation in stage at diagnosis.

Survival

Net survival rates for 2013 to 2017 diagnoses of ovary, fallopian tube and primary peritoneal carcinomas excluding borderline tumours

The following are net survival rates for 2013 to 2017 diagnoses in England of ovary, fallopian tube and primary peritoneal carcinomas (C56-C57, C48 excluding sarcomas), excluding all borderline tumours and excluding all tumours coded to D39.1 in ICD-10. See Appendix 1 for cohort definition in terms of ICD-10 and ICD-O-2 codes. All rates are net rates, age standardised with International Cancer Survival Standard (ICSS) weights. Net survival rates compare the survival of cancer patients with that of the general population. See Appendix 3 for more information on survival methodology.

Survival data by STP, Cancer Alliance, NHS Region and for all of England are available in the accompanying Excel workbook.

Net survival rates of patients with ovary, fallopian tube and primary peritoneal carcinomas excluding borderlines at one and 5 years, 2013 to 2017 diagnoses

For ovary, fallopian tube and primary peritoneal carcinomas, excluding borderlines in all of England, the one-year net survival rate was 68.0%, and the 5-year net survival rate was 34.6%.

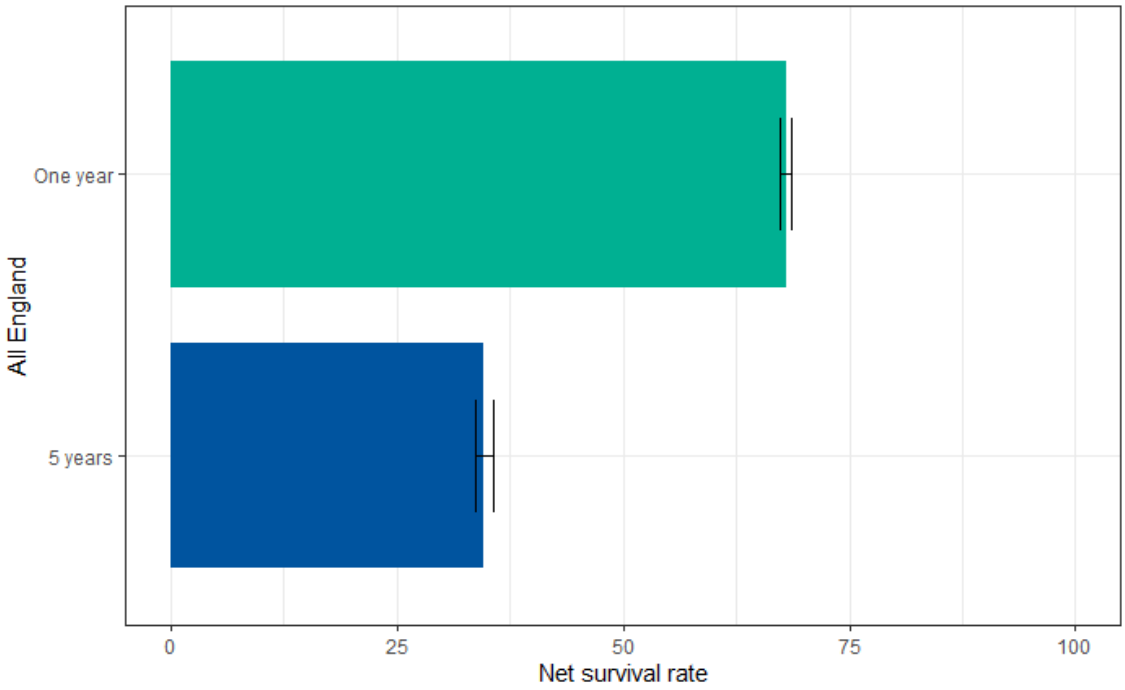


Figure 9. Net survival rates of patients with ovary, fallopian tube and primary peritoneal carcinomas excluding borderlines at one and 5 years, England, 2013 to 2017 diagnoses (Source: CAS AV2017)

Net survival rates of patients with ovary, fallopian tube and primary peritoneal carcinomas excluding borderlines at one and 5 years by Cancer Alliance, 2013 to 2017 diagnoses

One-year net survival for the 19 Cancer Alliances varied between 62.9% and 75.2%, 5-year net survival varied between 28.6% and 49.6%.

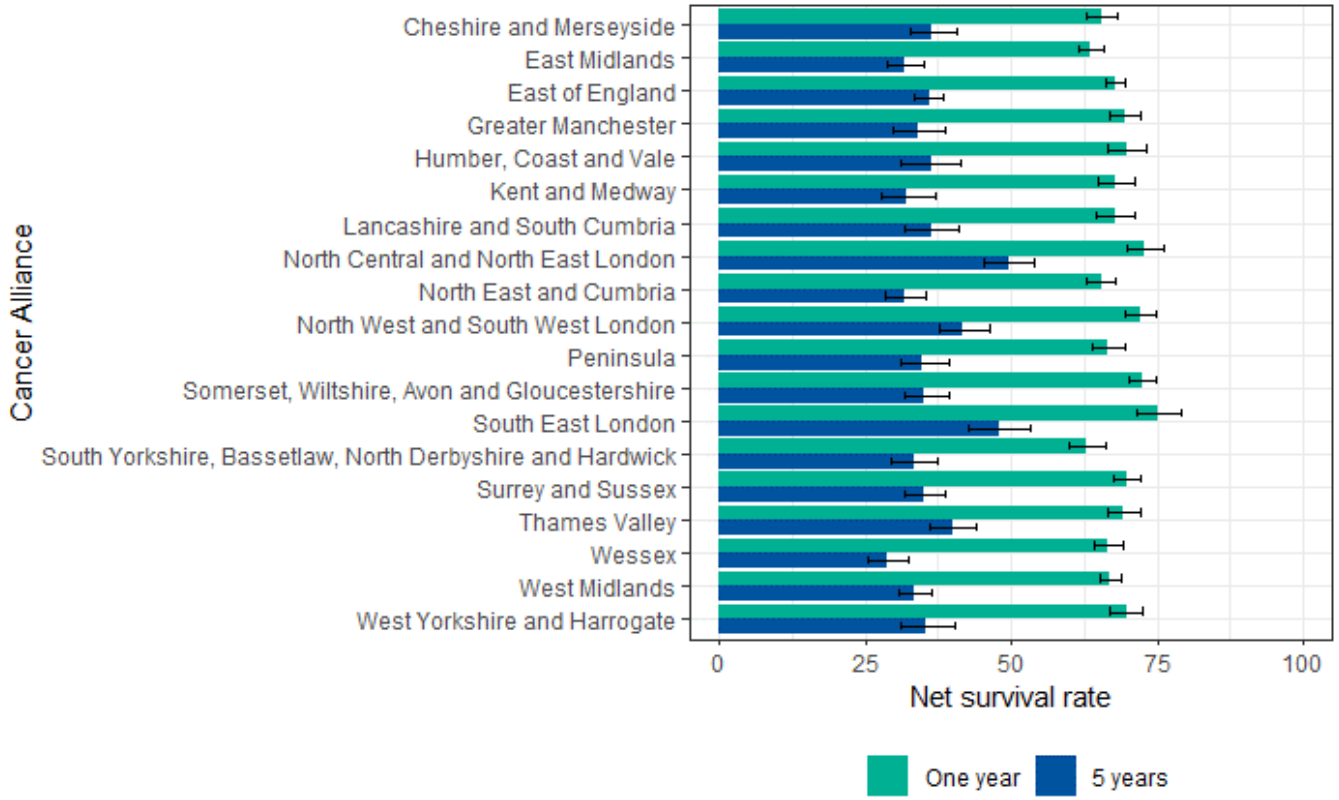


Figure 10. Net survival rates of patients with ovary, fallopian tube and primary peritoneal carcinomas excluding borderlines at one and 5 years by Cancer Alliance, 2013 to 2017 diagnoses (Source: CAS AV2017)

Variation in survival between regions may suggest possible variation in the quality of treatment (surgery and chemotherapy) between different gynaecological cancer centres. However, survival is also dependent on many other factors, including the profile of the population being treated and access to care. For example, there are differences in age, general health (including comorbidities), ethnicity and socioeconomic profiles of different regional populations across England, which could all impact on survival following a diagnosis of ovarian cancer. Additionally, there may be variation in the provision of primary care which would restrict access for patients in some areas to primary care services.

One-year survival is often considered to be an indicator of late presentation of malignancy, with poor one-year survival associated with diagnosis at late stage. In ovarian cancer, the patient's ability to undergo treatment once diagnosed (measured by

their WHO performance status score) is an important indicator of late diagnosis. If data completeness allows, performance status will be used in the planned output on short-term mortality. Five-year survival is more likely to reflect the quality of treatment administered by the gynaecological cancer MDTs, in addition to the other associated factors mentioned above.

One of the principal aims of the Ovarian Cancer Audit Feasibility Pilot is to explore these complex factors in order to understand variations in treatment approaches between Cancer Alliances. We will explore whether the survival variation seen in these charts can be fully explained by population factors, or whether there are examples of best practice in ovarian cancer management in some areas of the country which could be extended to other regions in order to improve outcomes for patients.

Net survival rates of patients with ovary, fallopian tube and primary peritoneal carcinomas including and excluding borderlines at one and 5 years, 2001 to 2017 diagnoses

One-year net survival for ovary, fallopian tube and primary peritoneal carcinomas excluding borderline tumours has increased from 57.5% for 2001 to 2005 diagnoses to 68.0% for 2013 to 2017 diagnoses. Five-year net survival estimates have also improved, from 25.7% for patients diagnosed in 2001 to 2005 up to 34.7% for patients diagnosed in 2013 to 2017.

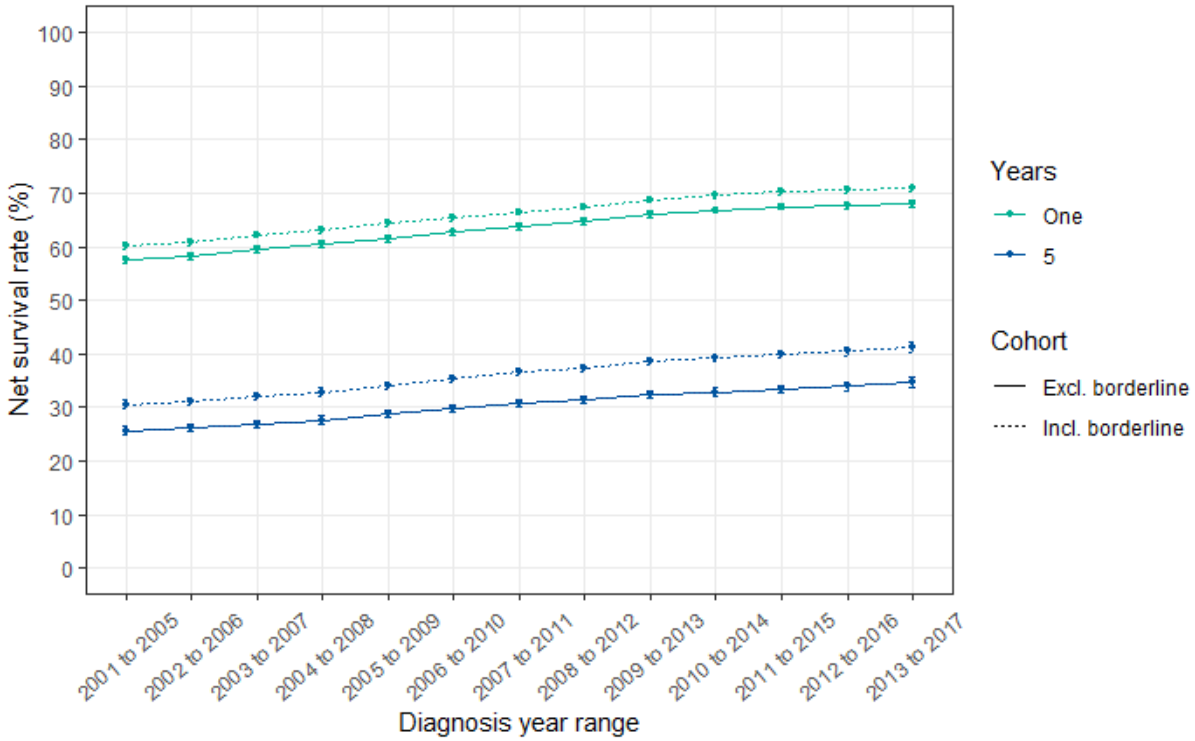


Figure 11. Net survival rates of patients with ovary, fallopian tube and primary peritoneal carcinomas including and excluding borderlines at one and 5 years, 2001 to 2017 diagnoses (Source: CAS AV2017)

The steady improvement in both one and 5-year survival rates for ovary, fallopian tube and primary peritoneal carcinomas likely represents improvements in various aspects of care in England since the turn of the century. Between 2000 and 2005 specialist gynaecological oncology centres with specialist MDTs were established throughout the country, providing access to centralised specialist surgery for all women regardless of where they live.

The major barrier to one-year survival remains access to timely diagnosis. Data from the Get Data Out programme indicates that patients diagnosed at stage 4 have lower survival rates and lower treatment rates than those diagnosed with earlier stage disease. This suggests that a proportion of women may be presenting too unwell from advanced disease to enable the specialist teams to administer effective chemotherapy or surgery. The improvement in one-year survival suggests that we may be starting to impact on this issue, likely due to increased awareness of symptoms amongst women and primary care practitioners, and improved diagnostic and early treatment pathways in secondary care. This project's future publications analysing Routes to Diagnosis and treatments for ovarian cancer in England will explore the impact of late diagnosis of very advanced disease on outcomes for patients.

The improvement in 5-year survival likely reflects not only improving access to treatment, but also improving effectiveness of ovary, fallopian tube and primary peritoneal carcinomas treatments. There are likely to have been real improvements in the quality of surgery available to women diagnosed with these diseases following the publication of the National Cancer Plan in 2000, with the establishment of specialist gynaecological cancer centres throughout England. Ovarian cancer surgery is now performed throughout the country by subspecialist accredited gynaecological oncology surgeons with specialist cancer surgery training. Surgical radicality for ovarian malignancies has generally increased during the past 2decades, and there have been a number of improvements in chemotherapy treatments for newly diagnosed and recurrent disease. Over recent years women have had access to new maintenance treatments which help to prevent disease recurrence. The precise contributions of each of these factors are unknown, but they have all likely had an impact in the improvement of 5-year survival and are likely to continue to do so in coming years.

Conclusion

This disease profile reviews all of the latest data (up to 2017 diagnoses) on incidence, mortality, stage at diagnosis and survival of patients with ovary, fallopian tube and primary peritoneal carcinomas in England.

Main findings:

- The incidence rate of ovary, fallopian tube and primary peritoneal carcinomas in England has remained reasonably stable since 2001.
- Incidence and mortality rates vary among CCGs and Cancer Alliances, with variation beyond what might be expected by random chance, suggesting that there may be genuine differences between areas.
- The proportions of patients diagnosed at early and late stages vary considerably around the country; some of this variability is likely due to data completeness but other factors should also be considered.
- Completeness of stage data varies by geography; there is some room for improvement which would lead to better data quality for reporting.
- Survival of patients with ovary, fallopian tube and primary peritoneal carcinomas has been improving since 2001. Improving one-year survival may reflect progress in diagnosing the disease sooner, with increased awareness of the symptoms amongst women and primary care practitioners, and improved diagnostic pathways, enabling more women to be diagnosed while still well enough to undergo treatment. Increased 5-year survival may reflect improvements in surgical and chemotherapy treatments. Assessment of geographic variation in survival rates may help to identify areas of best practice and improve the outlook for all patients.

By using NCRAS data to analyse the full cohort of ovary, fallopian tube and primary peritoneal carcinomas and including or excluding borderline tumours as appropriate, we have been able to make clear comparisons between geographies and over time.

Building on this new understanding, the ovarian cancer audit feasibility pilot will work to gain further insight into the factors behind the observed geographic variation and into best practices in the diagnosis and treatment of ovary, fallopian tube and primary peritoneal carcinomas, aiming for improved outcomes for patients.

Reporting on data completeness back to clinical staff in the NHS via the CancerStats website is an ongoing part of the ovarian cancer audit feasibility pilot work. Improving the quality of data available to NCRAS about patient performance status, stage, residual disease and surgeon grade will enable further valuable analysis to be undertaken.

Proposed further work for the ovarian cancer audit feasibility pilot includes study of variation in Routes to Diagnosis, treatment pathways, surgery and short-term mortality

for patients with ovary, fallopian tube and primary peritoneal carcinomas with respect to geographies, age and other factors.

Appendices

Appendix 1: Cohort definitions

Ovary, fallopian tube and primary peritoneal carcinomas (incidence and stage)

The cohort of ovary, fallopian tube and primary peritoneal carcinomas used for this Ovarian Cancer Audit Feasibility Pilot is all tumours coded in ICD-10 and ICD-O-2 to

C56 (Malignant neoplasm of ovary),
C57 (Malignant neoplasm of other and unspecified female genital organs),
C48 (Malignant neoplasm of retroperitoneum and peritoneum), excluding sarcomas: 8693, 8800, 8801, 8802, 8803, 8804, 8805, 8806, 8963, 8990, 8991, 9040, 9041, 9042, 9043, 9044, 8810, 8811 – 8921, 9120 – 9373, 9490, 9500, 9530 – 9582,
D39.1 (Neoplasm of uncertain or unknown behaviour of ovary).

Only female patients are included in the cohort.

This definition aligns with international ovarian cancer analyses and is designed to capture all ovarian cancers; although there may be variation in the coding of the originating site within this group, in practice their prognosis and treatment are similar. The inclusion of D39.1 means that the cohort includes all ‘borderline malignant’ ovarian cancer.

Ovary, fallopian tube and primary peritoneal carcinomas (excluding borderlines) (survival)

Borderline malignant (“borderline”) ovarian tumours make up approximately 16% of the overall cohort of ovary, fallopian tube and primary peritoneal carcinomas. These tumours have historically been recorded as ovarian cancers, though their malignant potential is now understood to be lower than the rest of the group.

Tumours with ICD-10 site code C56, C57 or C48 are defined as ‘borderline’ if their morphology code in ICD-O-2 is 8442, 8444, 8451, 8463, 8473, 8472 or 8462. Tumours with ICD-10 site code D39.1 are defined as ‘borderline’ if their morphology code in ICD-O-2 is 8144, 8260, 8313, 8380, 8381, 8440, 8441, 8460, 8470, 8480, 8481, 9000, 9013, 9014 or 9015. However, all tumours at ICD-10 site code D39.1 are excluded from survival analysis in line with National Statistics methodology.

In this report, survival analysis is presented for cohorts including and excluding borderline tumours. Their exclusion is in line with international ovarian cancer analyses

and avoids inflation of the survival estimates due to the better survival of the borderline group. Hence, it gives a clearer picture of the survival of women with non-borderline ovarian cancer. We have provided data for the cohort both including and excluding borderline tumours to provide comparability to outputs that do not exclude borderlines.

Ovarian cancer (mortality)

The definition of ‘ovarian cancer’ used for mortality statistics in this report is C56-C57 in ICD-10. Data on mortality from ovarian cancer are derived from the ONS Mortality Extract which is in turn derived from causes of death recorded on death certificates, which do not include morphology information. Hence the more nuanced cohort descriptions (as used for incidence, stage and survival) which rely on tumour morphology information are not available for this statistic.

Appendix 2: Stage

Stage presented in this report is ‘registry stage’: the stage at diagnosis of the tumour. Registry stage is primarily provided by the diagnosing trust via the MDT; the registry will review this stage and read pathology reports and clinical investigations to record the most accurate stage at diagnosis possible.

The 2 main staging systems used for ovarian cancer are FIGO and TNM. Where FIGO registry stage is available, this is used; otherwise TNM registry stage is used.

Appendix 3: Survival methodology

Net cancer survival rates (i.e. estimated survival rates as if cancer were the only possible cause of death) were calculated in a relative survival framework using a complete approach with follow-up to 5th January 2019. Results were age standardised using ICSS weights where numbers permitted. Cancer Survival SOP v11_0 was followed, using stns in Stata 15.1.

Appendix 4: Glossary

Age standardised rate, Directly standardised rate	ASR, DSR	Age standardised rates are used to compare rates for different populations accounting for differences in age distribution. They identify differences between populations which are not due to differences of their age distributions. Directly standardised rates are a specific way to calculate age standardised rates using a 'standard' population (European Standard Population 2013) as a reference. Directly standardised rates adjust for age by assuming that the age distribution of the population being studied is the same as that of the standard population. This enables direct comparisons between populations with different age profiles. Directly age standardised rates are used for incidence, mortality and survival rates in this report.
Borderline/non-Borderline		Borderline ovarian tumours are abnormal cells that form in the tissue covering the ovary. They are different to ovarian cancer because they do not grow into the supportive tissue of the ovary (the stroma). They tend to grow slowly and in a more controlled way than cancer cells. The main treatment for borderline tumours is surgery. Most women are cured and have no further problems. There is a small risk of the tumour coming back. Very rarely, the borderline tumour cells change into cancer cells.
Cancer Alliances	CA	The 19 Cancer Alliances in England bring together the key organisations in their regions to coordinate cancer care and to plan for and lead delivery of improved outcomes for patients locally.
Cancer Analysis System	CAS, AV	The Cancer Analysis System is the database system maintained and used by the National Cancer Registration and Analysis Service, containing data on all tumours registered in England. Versions of the CAS are indicated by "AV" with a numerical indication of the date of the data. Data in this report are derived from the CAS. Further documentation can be found in the Data Resource Profile cited below.
Cancer registry	NCRAS	The National Cancer Registration and Analysis Service (NCRAS) collects data on all cases of cancer that occur in people diagnosed in England. The data is used to support public health, healthcare and research.
Carcinoma		Category of types of cancer that develop from epithelial cells.

Clinical Commissioning Groups	CCGs	Clinical Commissioning Groups (CCGs) commission most of the hospital and community NHS services in the local areas for which they are responsible. Commissioning involves deciding what services are needed for diverse local populations and ensuring that they are provided. All GP practices now belong to a CCG, but CCGs also include other health professionals, such as nurses.
Comorbidity		A disease or condition that someone has in addition to the health problem being studied or treated (i.e. cancer).
Complete approach		Method of survival analysis that includes all patients diagnosed until the end of a maximum follow up time.
Count		Number of patients or of tumours with relevant characteristics.
Crude rate		Rate derived directly from the counts of relevant patients/tumours and the size of the population. For example, the crude incidence rate of ovarian, fallopian tube and primary peritoneal carcinomas in 2017 is the number of such tumours diagnosed divided by the number of women alive in England in that year. Because cancer is not common, this is often multiplied up and expressed as a count per 100,000 person-years.
Emergency Presentation		An emergency presentation is a diagnosis of cancer that arose from an unscheduled (or emergency or unplanned) hospital admission. This is to be contrasted with other Routes to Diagnosis, for example, diagnosis via referral from a GP.
Fallopian tube		Fallopian tubes carry eggs from the ovaries to the uterus. Serous carcinomas of the fallopian tube are considered to be the same disease entity as serous cancers of the ovary and primary peritoneal carcinoma, which is why cancers at all 3 sites are collected in this report.
FIGO stage	FIGO	System for staging of gynaecological cancers, published by the International Federation of Gynaecology and Obstetrics (FIGO).
ICD codes	ICD	International Classification of Diseases is a medical classification and coding list for the identification of diseases, signs and symptoms, abnormal findings, complaints, social circumstances and external causes of injury or diseases, as maintained by the World Health Organization (WHO).

		ICD-10 classifies cancers by site and behaviour (malignancy) and ICD-O classifies cancers by site, morphology and behaviour.
Incidence		The number of new cases of cancer, usually expressed as a rate by dividing by the total population at risk during a certain period.
International Cancer Survival Standard weights	ICSS	Weights used for age standardisation of survival data for cancer. The weights reflect the age distribution for the cancer population considered, rather than the population at large.
Malignant		Malignant tumours are considered to be cancer. Malignant means characterised by the tendency to become progressively worse. Often characterised by anaplasia, invasiveness and /or metastases.
Morphology		Morphology is the type of a tumour, as diagnosed by a pathologist looking at the shape of the cells through a microscope. The morphological type of a tumour can be important in understanding how to treat that tumour and what expected outcomes might be.
Mortality		Cancer mortality is the number of deaths from cancer in a specific population within a specific period of time, usually a year. It usually only includes deaths where cancer is mentioned as an underlying cause of death on death certificates. Cancer mortality is often expressed as a crude or age standardised rate. Cancer mortality rates are a standard measure of the frequency of deaths from cancer within a specific period of time relative to a fixed population size, usually 100,000 person-years.
Multidisciplinary team	MDT	MDTs bring together experts in specific areas of medicine and care, and usually meet every week to discuss the diagnosis, treatment and care of individual cancer patients.
NHS Long Term Plan		The NHS Long Term Plan was published in January 2019 and sets out major goals for the NHS over the following 10 years. This includes some cancer-specific targets, notably a goal to diagnose 75% of all cancers at early stage (stages 1 to 2) by 2028.
NHS trusts		NHS hospital trusts are organisational units within the National Health Service in England, providing secondary health services in a particular local area.
Performance status		Performance status is an attempt to quantify cancer patients' general well-being and activities of daily life. This is captured as a WHO (World Health Organization) score between 0 and 5.

Peritoneum	C48	The peritoneum is the serous membrane forming the lining of the abdominal cavity. Primary peritoneal carcinomas are considered to be the same disease entity as serous carcinomas of the ovarian or fallopian tube, which is why cancers at all 3 sites are collected in this report.
Person-years		The size of the population in each year, summed over years. Using person-years for populations when calculating incidence and mortality rates allow us to compare rates from different lengths of time.
Primary peritoneal carcinomas		Cancer of the epithelial cells in the peritoneum. Primary peritoneal carcinomas are considered to be the same disease entity as serous carcinomas of the ovarian or fallopian tube, which is why cancers at all 3 sites are collected in this report.
Stage		Stage describes the extent or severity of a person's cancer. Diagnosis at earlier stage leads to improved prognosis, treatments and outcomes in comparison with cancers diagnosed at a later stage.
Standard population	ESP2013	Standard population is an example distribution of ages in the population and is used for direct age-standardisation. (See "Age standardised rate" above.) This report uses the European Standard Population 2013.
Survival		Crude survival rates are calculated as the number of patients who survive a certain length of time since their diagnosis, divided by the total number of patients in the group. Net survival rates, published here, are survival rates adjusted so that they better estimate the proportion of patients dying of cancer rather than other causes.
Sustainability and Transformation Partnership	STP	The 44 STPs are areas (covering all of England), where local NHS organisations and councils have drawn up shared proposals in their locality to improve health and care in the areas they serve in partnership.
World Health Organization	WHO	The World Health Organization directs and coordinates international health within the United Nations system. The WHO classification systems for cancer sites (ICD-10, ICD-O) and performance status are used in the cancer registry.

Appendix 5: Useful links

Ovarian Cancer Audit Feasibility Pilot homepage *Information about this project and links to outputs.*	http://ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/ovarian_cancer_audit_feasibility_pilot
NCRAS gynae hub ovarian cancer resources *Reports, briefings and other resources on ovarian cancer from NCRAS.*	http://ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/resources/ovarian_cancer
CancerData *NCRAS hub for incidence and mortality data by geographies, Routes to Diagnosis and treatment data for cancers including ovary.*	https://www.cancerdata.nhs.uk/incidence https://www.cancerdata.nhs.uk/mortality https://www.cancerdata.nhs.uk/routestodiagnosis https://www.cancerdata.nhs.uk/treatments
CancerStats I *For N3 (NHS) connections only, requires signup. Incidence and mortality with greater geographical granularity than CancerData.*	https://nww.cancerstats.nhs.uk/
CancerStats II *For N3 (NHS) connections only, requires signup. Select Audits > OCAFP for project outputs including data completeness report.*	https://cancerstats.ndrs.nhs.uk/
Data Resource Profile: National Cancer Registration Dataset in England *Information about the registry dataset used for this report.*	https://doi.org/10.1093/ije/dyz076

Get Data Out: Ovary, fallopian tube and primary peritoneal carcinomas *Routine data from NCRAS on small groups of ovarian cancer patients since 2013. Incidence, Routes to Diagnosis, treatment, survival.*	https://www.cancerdata.nhs.uk/getdataout/ovary https://www.cancerdata.nhs.uk/getdataout/data
Progress in cancer survival, mortality, and incidence in seven high-income countries 1995–2014 (ICBP SURVMARK-2): a population-based study, The Lancet Oncology, Arnold et al. 2019 *International comparison of cancer incidence, mortality and survival, including ovarian cancer.*	https://doi.org/10.1016/S1470-2045(19)30456-5
Stage breakdown by CCG 2017 *NCRAS stage data for sites including ovary, split by CCG.*	http://www.ncin.org.uk/view?rid=3864