NDRS
NATIONAL DISEASE REGISTRATION SERVICE

Ovarian Cancer Audit Feasibility Pilot

Project summary report: lessons learned on the feasibility of a national ovarian cancer clinical audit utilising only existing cancer registry, SACT and HES data

About the NDRS

The National Disease Registration Service (NDRS) is part of NHS England (NHSE).
Its purpose is to collect, collate and analyse data on patients with cancer, congenital anomalies, and rare diseases. It provides robust surveillance to monitor and detect changes in health and disease in the population. NDRS is a vital resource that helps researchers, healthcare professionals and policy makers make decisions about NHS services and the treatments people receive.

The NDRS includes:

- the National Cancer Registration and Analysis Service (NCRAS) and
- the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Healthcare professionals, researchers and policy makers use data to better understand population health and disease. The data is provided by patients and collected by the NHS as part of their care and support. The NDRS uses the data to help:

- understand cancer, rare diseases, and congenital anomalies
- improve diagnosis
- plan NHS services
- improve treatment
- evaluate policy
- improve genetic counselling

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This work uses data that has been provided by patients and collected by the NHS as part of their care and support. The data are collated, maintained and quality assured by the NDRS, which is part of NHS England.

Background

The Ovarian Cancer Audit Feasibility Pilot (OCAFP) was a three-year collaboration between the gynaecological oncology clinical community, the charity sector and NHS Digital, conducted over the period from 2019 to 2023. During this time, a range of outputs on ovarian cancer have been reported. These can be found on the project webpage.[1]

The primary objective of the OCAFP was to explore whether it would be possible to undertake meaningful analyses of routinely collected data for the purpose of improving treatment and outcomes for women diagnosed with ovarian cancer in England – the leading cause of gynaecological cancer death for women in England.[2] In achieving this, the project aimed to make the case for an ongoing, publicly funded ovarian cancer audit. This goal was met when the Healthcare Quality Improvement Partnership (HQIP) announced a national ovarian cancer audit in 2022. The methodologies, successes, limitations, and associated intelligence from the OCAFP are now able to inform the development of the national ovarian cancer audit, which has the potential to build-on and extend the achievements of the OCAFP over the coming years.

The OCAFP was jointly funded by the British Gynaecological Cancer Society, Target Ovarian Cancer and Ovarian Cancer Action, and delivered by analysts within NHS Digital's National Disease Registration Service (NDRS). A Project Steering Group (PSG) met quarterly and oversaw the scope and direction of the pilot with input from senior representatives of each partner organisation. The day-to-day running of the pilot was managed by the Project Management Group (PMG), which comprised representatives of the four organisations and met monthly. We believe that this project has been a unique and highly significant achievement, demonstrating that the English clinical community and patient charities can come together with the support of NDRS to substantially improve the evidence required to improve patient care.

Over the course of the pilot, a programme of analytical projects was delivered that exclusively utilised existing data routinely collected during clinical practice and disease registration. Unadjusted and adjusted results were reported for each project, with regional variation in incidence, treatment, survival, and mortality all presented by Cancer Alliance. Where sufficient data were available, geographic variation was also reported by Clinical Commissioning Group (CCG), with granular unadjusted data made available to NHS employees at a provider level via the CancerStats2[3] website.

This project summary report provides an overview of these projects, their impact on clinical practice and patient outcomes, and the limitations of the routine data sources that prohibited or limited some aspects of the project. The learning presented in this report is not only intended to support the development and scoping of the forthcoming national ovarian cancer audit, but also others seeking to utilise the national cancer data resources for the analysis of ovarian cancer, and those looking to utilise existing data items for other cancer sites and diseases. We believe that this is the first feasibility pilot of its type in England.

The first publication from the OCAFP was a Disease Profile Report, which describes ovarian cancer incidence, survival, and mortality across England. The second publication includes an analysis of surgery and chemotherapy rates across England, indicating variation in access to treatment between Cancer Alliances. The third report focuses on short-term mortality, describing variation in cases of death from ovarian cancer within 12 months of diagnosis. All three publications had a profound impact within the gynaecological cancer community, with

evidence that the findings have been a lever for change and service improvement. Many Cancer Alliance gynaecology tumour site specific groups (TSSGs) and individual specialist gynaecological cancer specialist multidisciplinary teams (MDTs) have used the OCAFP data to benchmark their performance and outcomes against national and other regional data. These data comparisons have been used as a mechanism to highlight processes and pathways which can be improved to improve outcomes for future cohorts of ovarian cancer patients.

A fourth project was planned with the aim of assessing regional variation in the radicality of surgical practice. Regrettably data validation processes indicated insufficient surgical data quality to support publication of such a report. This summary document includes an overview of the planned methodology and the limitations identified. Learning from this exercise will inform changes and improvements to the routine capture of surgical data for ovarian cancers, hopefully enabling a future investigation into surgical practice and its variation across England.

Disease Profile in England: Incidence, mortality, stage and survival for ovary, fallopian tube and primary peritoneal carcinomas (January 2020)

Objective

To describe the incidence, stage, mortality and survival profile of ovarian, fallopian tube and female primary peritoneal cancers (hereafter 'ovarian cancer') including geographical variation thereof.

Method

Incidence rates are described for cases diagnosed in England between 2015-2017, with stratification by stage at diagnosis. Survival is reported for cases diagnosed during the same period, with one- and five-year net survival rates reported for cases diagnosed 2013-2017. Incidence and survival are also reported for the 2001-2017 diagnoses, allowing for an exploration of longer-term trends. Mortality is reported for deaths occurring during 2015-17.

Directly age-standardised rates are included for incidence and mortality figures to allow the comparison of rates across Cancer Alliances, Sustainability and Transformation Partnerships (STPs) and CCGs.

Analyses utilised routine data available in the National Cancer Registration Dataset (NCRD), which captures information on all cancer diagnoses in England, including pathology details, patient and tumour characteristics, death certificates and important clinical parameters such as disease stage.

Limitations

Completeness of stage data varied substantially by geography. Improved capture of staging determined by multidisciplinary teams would lead to better data quality for reporting. Mortality reporting is also limited by a lack of granularity of coding on death certificates, which is restricted to ICD-10 codes only. This contrasts with cancer registrations, which incorporate morphological coding.

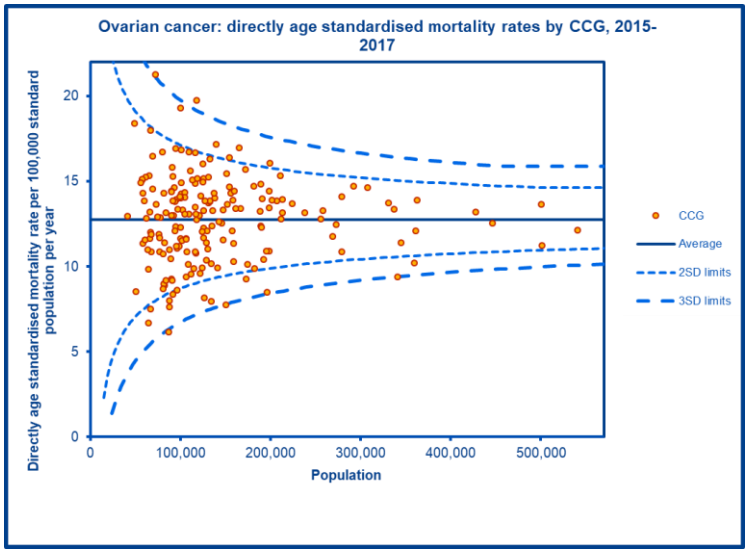
Findings

The main findings of the report were:

- The incidence rate of ovary, fallopian tube and primary peritoneal carcinomas in England remained reasonably stable between 2001 and 2017.
- Incidence and mortality varied among CCGs and Cancer Alliances, with rates in some areas varying from the population average by magnitudes greater than might be expected by chance (2 standard deviations (SD) or more from the average). Data is presented, as shown in Figure 1. Here, statistical outliers are shown above and below

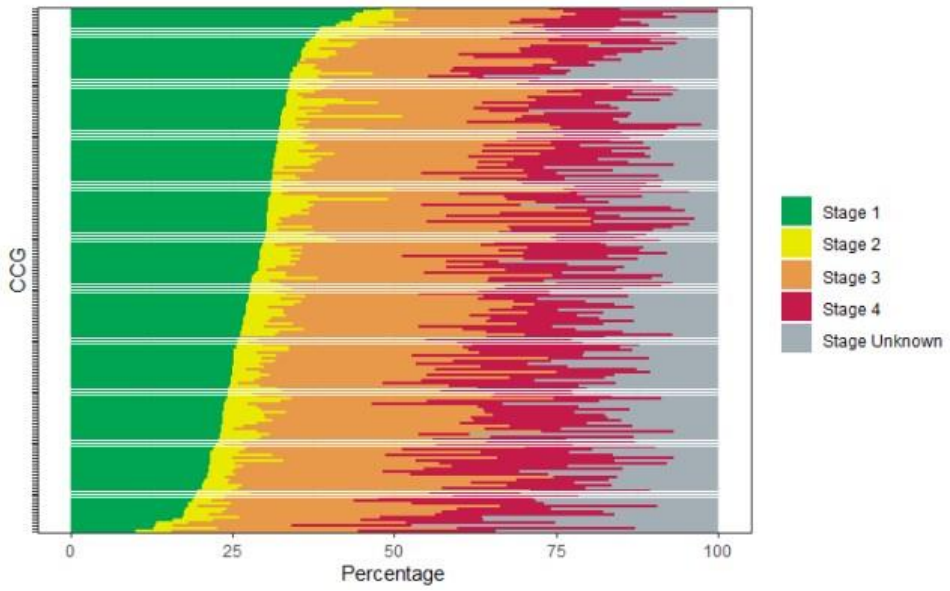
the dotted lines representing positions greater than two standard deviations (SD) from the population average. Larger population geographies are situated towards the right-hand side of the plots, where the lines of the funnel plot converge as population size and statistical certainly increase. Statistically significant outliers suggest that there may be genuine differences between areas that merit further investigation at a local level.

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



- The proportions of patients diagnosed at early and late stages varied considerably around the country; some of this variability is likely due to data completeness but other factors should also be considered (Figure 2).

Figure 2 Stage at diagnosis of ovary, fallopian tube and primary peritoneal carcinomas by CCG, 2015 to 2017

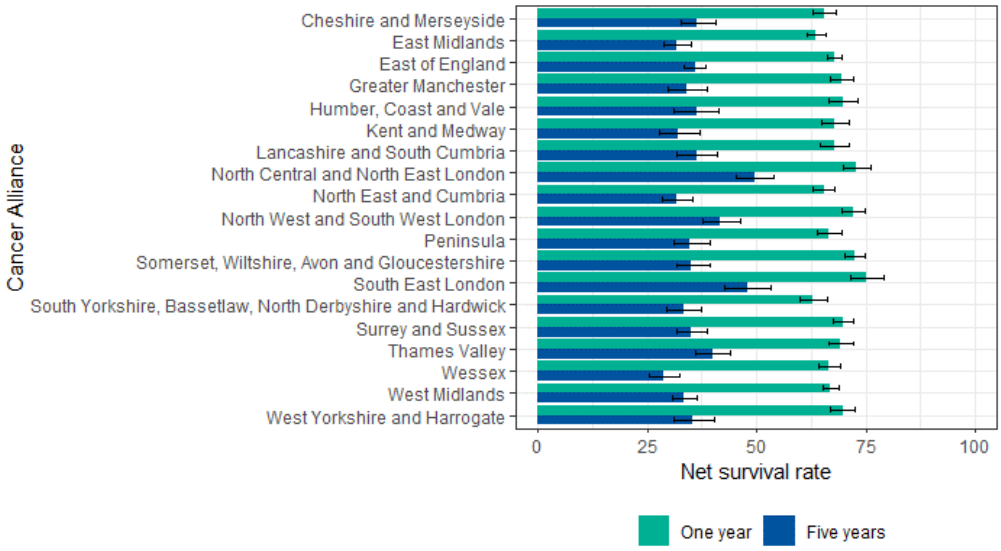


- Survival of patients has been improving since 2001, with one-year net survival having increased from 57.5% for diagnoses in 2001-2005 to 68.0% for patients diagnosed in the period 2013-2017. In contrast to some previously reported survival figures, these exclude borderline tumours which generally have an excellent prognosis and include primary peritoneal malignancy which is commonly associated with poor outcomes. This

improvement in 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 healthy enough to undergo treatment. Five-year survival was also observed to have increased, which may reflect improvements in surgical and chemotherapy treatments.

- Survival varied significantly between the 19 Cancer Alliances. One-year net survival ranged between 62.9% and 75.2%, and five-year net survival varied between 28.6% and 49.6%.

Figure 3 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



Geographic variation in ovarian, fallopian tube and primary peritoneal cancer treatment in England (November 2020)

Objective

One possible reason for regional disparities in age-standardised one- and five-year survival was variation in the local clinical management of disease. To explore this hypothesis, a report was produced that describes geographic variation in treatment between Cancer Alliances in England, and the extent to which these might be explained by regional differences in tumour and patient characteristics.

Results were also produced at a provider level and made available to NHS staff via the CancerStats2[3] website for circulation within gynaecological cancer multidisciplinary teams.

Support was provided through data liaison teams to provide help with retrospectively updating and prospectively improving treatment data quality and completeness.

Method

A cohort of ovarian cancers was created using data from the NCRD. Diagnoses in England were selected for the period between 2016 and 2018.

Where data were available, each tumour was linked to information describing the delivery of systemic anti-cancer therapy (hereafter 'chemotherapy') or major surgical resection during the primary (i.e., first) course of treatment, defined as treatment initiated during the nine months following diagnosis. These treatment data were obtained from the NCRD in the first instance and supplemented with additional routine data available through the Systemic Anti-Cancer Therapy (SACT) and Hospital Episode Statistics (HES) datasets.

Based on the type and ordering of treatment received, four binary treatment categories were created:

1. Any treatment versus no treatment
2. Surgery versus no surgery
3. Chemotherapy versus no chemotherapy
4. Primary surgery with adjuvant chemotherapy (i.e., surgery followed by chemotherapy) versus neoadjuvant chemotherapy with interval debulking surgery (i.e., chemotherapy first followed by surgery).

Each binary treatment category was included as an outcome in a linear probability model, adjusted for a range of patient factors associated with clinician and patient decision making. Results are interpretable as the percentage-point difference in the probability of treatment relative to the cohort average.

Stage 1 tumours were omitted from these analyses owing to a lack of variability in treatment for early-stage cancers (96.3% were treated with either primary surgery only, or primary surgery and adjuvant chemotherapy).

Three different levels of adjusted were applied:

- Model 1: an unadjusted analysis, comparing crude treatment probabilities for tumours diagnosed within each Cancer Alliance.
- Model 2: adjusted for differences between Cancer Alliances in the distribution of patient age, tumour morphology and tumour stage.
- Model 3: adjusted for the same factors as Model 2, plus area income deprivation and Charlson comorbidity score.

Limitations

Linear probability models were adjusted to estimate geographic variation in treatment independent of differences in patient factors likely to differ between regions and influence the treatment pathway. Despite this, any observed geographic differences in treatment may be attributable to residual confounding rather than real disparities in clinical practice, such as differential routes to diagnosis (data unavailable at the time of analysis) or geographic differences in patient frailty (data not captured).

There were challenges with both the Charlson comorbidity index and patient performance status at diagnosis. The index scored a pre-defined subset of chronic comorbid conditions based on diagnosis codes extracted from HES Admitted Patient Care (APC) data. Although the index is known to correlate with patient treatment and survive, it does not capture the full burden of comorbid illness. For example, of the 17,155 tumours selected in the cohort, 82.8% (n=14,196) were assigned a comorbidity score of zero. Performance status, a key prognostic indicator, could not be included in the models described above due to high levels of missing data (57.9%). This was despite repeated outreach to the clinical community to stress the importance of routine capture of this data item by multidisciplinary teams.

Reported analyses do not consider treatments provided in private healthcare settings. Due to the absence of private healthcare data, tumours registered by multidisciplinary teams and subsequently treated in private institutions will have been incorrectly assigned to the ‘no major surgical resection or chemotherapy’ category. Accordingly, the true proportion of tumours that received treatment will be higher than reported, and with the possibility of differences in private treatment access between Cancer Alliances.

Findings

The most striking finding of this study was that within the overall cohort of 17,155 tumours, 21.9% (n=3,751) received no surgery nor chemotherapy.

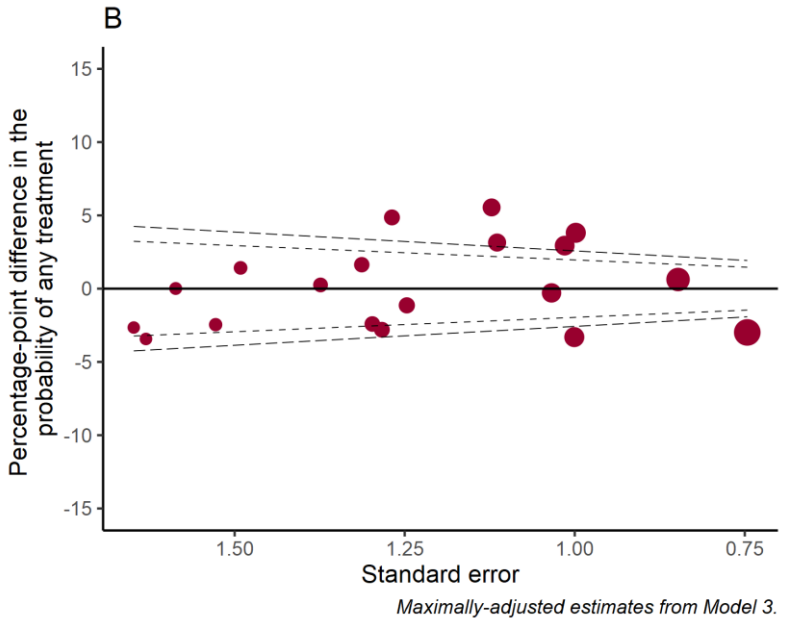
Regarding patient demographics and tumour characteristics:

- Tumours with missing stage data or stage 4 disease were much less likely to receive any treatment, with 28.2% and 60.7% respectively having received neither chemotherapy nor surgery.
- Women with tumours classed as miscellaneous and unspecified were less likely to receive any treatment, with 89.1% receiving neither surgery nor chemotherapy.

- Women with underlying medical conditions, identified by the Charlson comorbidity index, were less likely to receive surgery. Of women with a score >2, 55.8% received neither surgery nor chemotherapy.
- Tumours in women aged >79 years were the least likely to receive any treatment, with 60.1% receiving neither chemotherapy nor surgery.

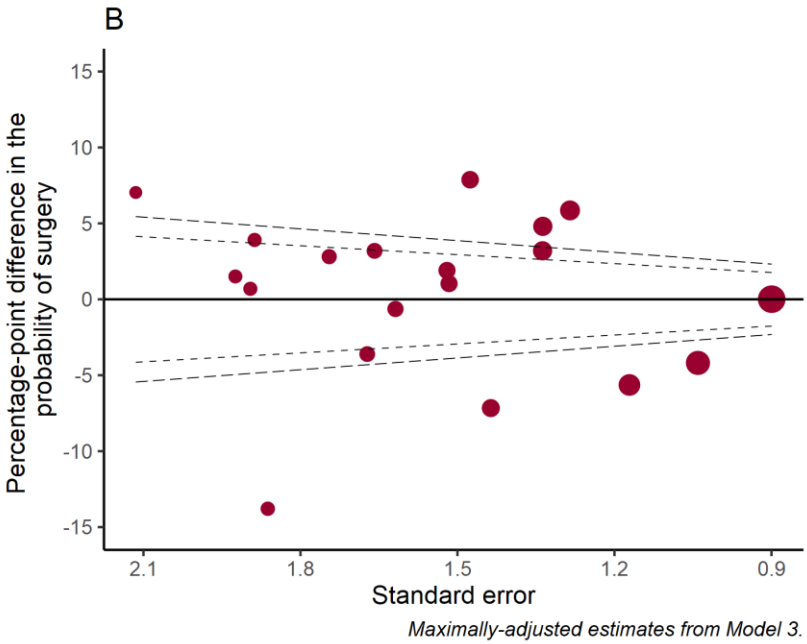
In terms of geographic variation, the weighted average probability of any treatment for stage 2-4 and unknown stage tumours was 73.8%. As shown in the funnel plot below, wide variations in the rates of any treatment were observed across Cancer Alliances even after adjustment for a range of factors associated with the treatment pathway.

Figure 4 Geographic variation in the probability of receiving any treatment versus no treatment, excluding stage 1 disease, 2016 to 2018



The average probability of stage 2-4 and unknown stage ovarian cancers having been treated with any surgery was 51.0%. The funnel plot below indicates large geographic variation in the delivery of surgery between Cancer Alliances, even after adjustment for other factors (Figure 5).

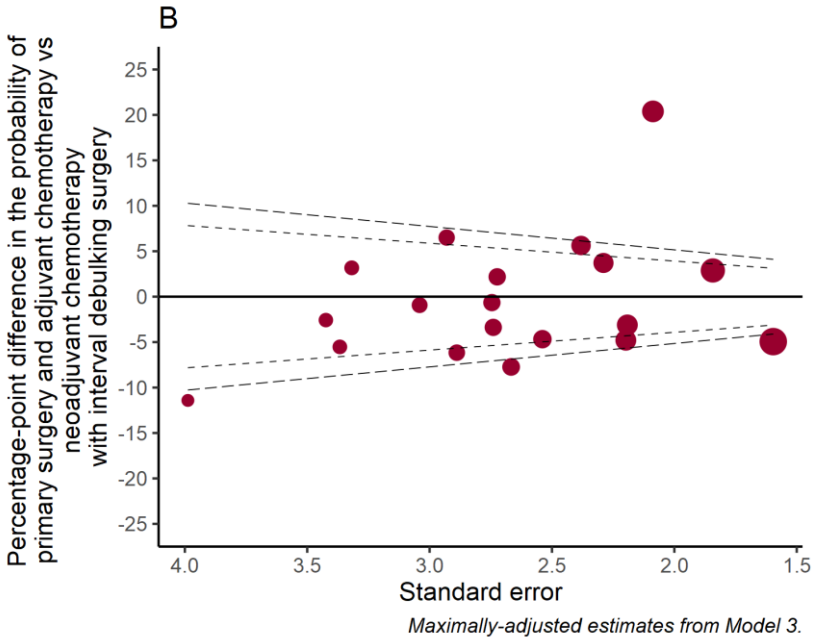
Figure 5 Geographic variation in the probability of receiving surgery versus no surgery, excluding stage 1 disease, 2016 to 2018



There was less variability with regard to chemotherapy treatment rates between the Cancer Alliances, indicating that variation in surgery rates was the main driver of the variability in overall treatment seen in Figure 4.

The analysis of primary surgery with adjuvant chemotherapy versus neoadjuvant chemotherapy with interval debulking surgery was restricted to the 6,065 tumours within the cohort of stage 2-4 and unknown stage cancers that were assigned to one of these two treatment groups. Of these tumours, the probability of primary surgery and adjuvant chemotherapy was 49.4% on average. Figure 6 shows the maximally adjusted probability of treatment with primary surgery and adjuvant chemotherapy.

Figure 6 Geographic variation in the probability of receiving primary surgery with adjuvant chemotherapy versus neoadjuvant chemotherapy with interval debulking surgery, excluding stage 1 disease, 2016 to 2018



The variation in any treatment, any surgery and any chemotherapy rates between Cancer Alliances is presented in Table 1. Cancer Alliances with rates two SDs above the national average are denoted in blue, and those with rates two SDs below are denoted in pink. This table provided clinical teams with ready comparison of their own Cancer Alliance performance and proved a powerful tool supporting engagement with the findings of the OCAFP.

Table 1 Summary of maximally adjusted geographic variation in any treatment, surgery and chemotherapy (Model 3; n=13,889), excluding stage 1 disease, 2016 to 2018

	Any treatment (n=13,889)		Any surgery (n=13,889)		Any chemotherapy (n=13,889)	
Variables	Estimate	p-value	Estimate	p-value	Estimate	p-value
Cohort average (intercept)	73.8	0.000	51.0	0.000	66.5	0.000
Cancer Alliance						
Cheshire and Merseyside	-2.4	0.063	1.0	0.495	-1.3	0.370
East Midlands	-3.3	0.001	-5.6	0.000	-2.5	0.024
East of England	-3.0	0.000	0.0	0.993	-3.4	0.000
Greater Manchester	-2.8	0.029	-3.6	0.031	-2.2	0.122
Humber, Coast and Vale	-2.5	0.108	3.9	0.038	-3.2	0.066
Kent and Medway	-3.4	0.035	0.7	0.714	-4.7	0.012
Lancashire and South Cumbria	1.4	0.342	1.5	0.434	-0.7	0.687
North Central and North East London	0.3	0.853	2.8	0.108	-0.5	0.742
North East and Cumbria	-0.3	0.780	3.2	0.017	0.3	0.814
North West and South West London	5.5	0.000	7.9	0.000	3.9	0.003
Peninsula	4.9	0.000	1.9	0.211	7.1	0.000
Somerset, Wiltshire, Avon and Gloucestershire	2.9	0.004	4.8	0.000	2.8	0.021
South East London	0.0	0.994	7.0	0.001	0.7	0.695
South Yorkshire, Bassetlaw, North Derbyshire and Hardwick	-2.7	0.108	-13.8	0.000	-0.5	0.761
Surrey and Sussex	3.8	0.000	5.9	0.000	0.7	0.591
Thames Valley	1.6	0.213	3.2	0.054	-0.2	0.889
Wessex	-1.1	0.361	-7.2	0.000	0.7	0.620
West Midlands	0.6	0.462	-4.2	0.000	1.8	0.045
West Yorkshire and Harrogate	3.1	0.005	-0.6	0.694	3.0	0.023

The cohort contains cases of ovarian, tubal and primary peritoneal cancer diagnosed between January 2016 & December 2018 inclusive. Stage 1, borderline and non-specific site tumours are excluded, along with cancers diagnosed via death certificate. Treatment data are compiled from the cancer registry, Hospital Episode Statistics (HES) admitted patient care dataset, and the Systemic Anti-Cancer Therapy (SACT) dataset. Data were captured during the primary course of treatment (the period up to nine months following diagnosis). Treatments dated outside of this window are not considered. In a small minority of cases, tumours were documented as receiving both systemic anti-cancer therapy and major surgical resection on the same day. These cases are coded to the neoadjuvant anti-cancer therapy treatment group.
Model 1 includes Cancer Alliance only; Model 2 as Model 1, plus adjustment for patient age, tumour morphology and tumour stage; Model 3 as Model 2, plus area income deprivation and Charlson comorbidity score.

Short-term mortality in ovarian, fallopian tube and primary peritoneal carcinomas across England

Objective

A disproportionately high number of women with ovarian cancer die within a year of diagnosis. To investigate the reasons behind this, a report was produced that explored the characteristics and prognostic factors of these women compared to those who survived longer than 12 months after diagnosis. Geographical variation in short-term mortality was also investigated.

Method

Data from the NCRD were used to identify women diagnosed with ovarian cancers (excluding borderline malignancies) in England between 2013 and 2018.

To examine how mortality rates changed over the first year after diagnosis, patients were assigned to four groups:

- Patients who died within 0 to 2 months from diagnosis
- Patients who died within 2 to 6 months from diagnosis
- Patients who died within 6 to 12 months from diagnosis
- Patients who survived more than 12 months following diagnosis

Crude mortality rates were calculated to examine the distribution of patient demographics and tumour characteristics across these short-term mortality groups. Factors were assessed for statistically significant differences in mortality via chi-squared tests. Mixed effects logistic regression models were fitted for each of the short-term mortality groups to estimate the association of statistically significant factors with short-term mortality in ovarian cancer patients. To examine geographical variation, crude and case-mix adjusted mortality rates for each Cancer Alliance were calculated.

Limitations

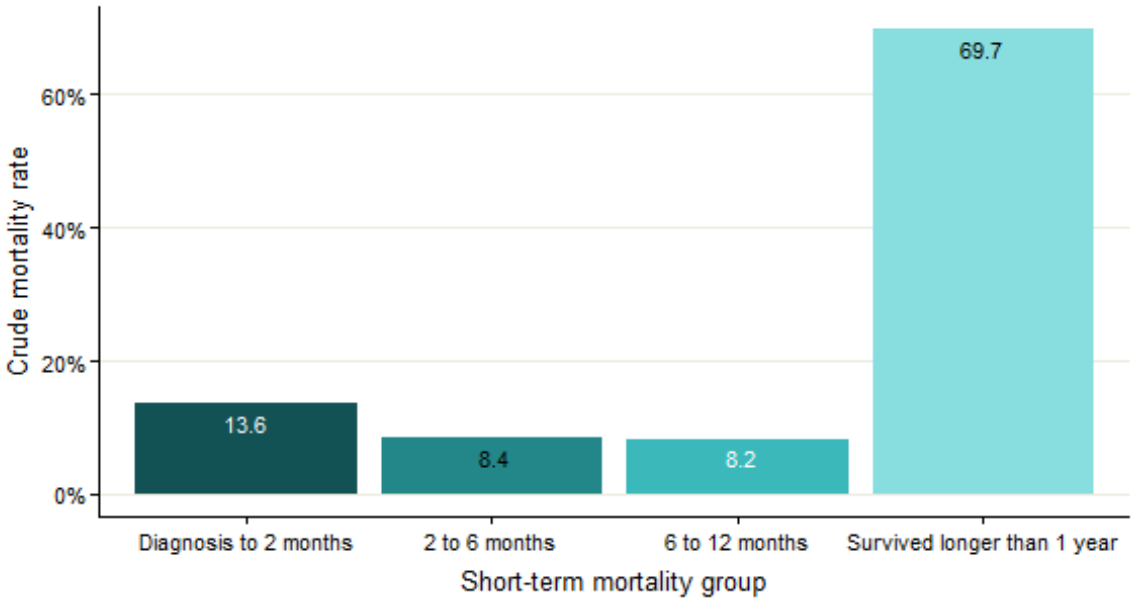
Data completeness rates for most data fields were generally good (>95% completeness). However, as for the treatment report cohort, the capture of performance status and stage at diagnosis was low, with data missing for 63.4% and 16.9% of patients respectively.

The derived Charlson comorbidity score correlated with short-term mortality but appeared to underestimate the true comorbidity burden of patients, with 84.3% of cases having been assigned a comorbidity score of zero, which is inconsistent with the age profile of the patient cohort.

Findings

Results from these analyses show that the short-term mortality rate for ovarian cancer patients remains high: 14% of women died within two months of diagnosis, and 30% died within the first year (**Figure 7**).

Figure 7 Short-tern mortality in patients diagnosed with ovary, fallopian tube or primary peritoneal carcinomas, 2013 to 2018



This compares to a previous analysis[2] of 2006-2008 cases,[4] published in 2013, which shows a 15% two-month and 31% 12-month mortality rate. However, the 2013 analysis included patients with borderline tumours (who typically exhibit excellent long-term prognosis) and excluded primary peritoneal cancer patients (who have a relatively high short-term mortality rate), suggesting a modest overall improvement in short-term mortality rates from ovarian cancer in England over the last decade.

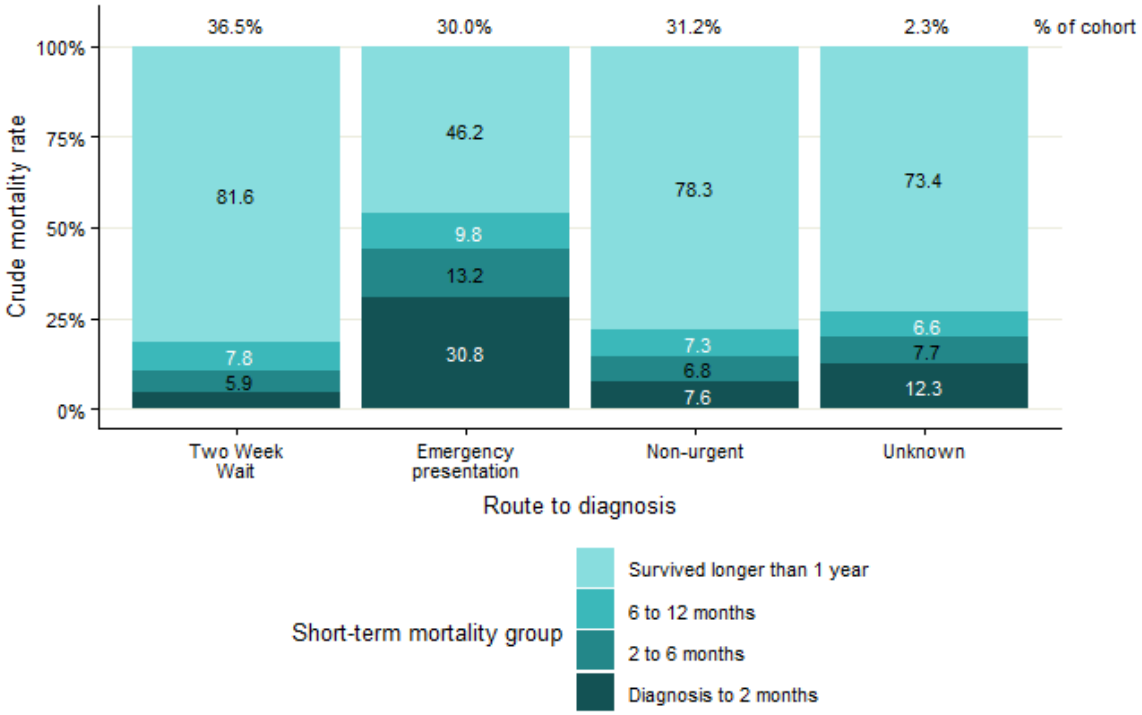
Mortality rates were impacted by several factors, with the greatest variation seen for women who died within two months following their diagnosis. For example:

- Older age: 15.7% of women aged 70-79 years and 34.8% of women aged ≥80 years died within two months of diagnosis. Adjusting for confounding factors, women aged ≥80 years at diagnosis were 40% more likely to die within two months than those aged 70-79 years.
- Women diagnosed at a later or unknown stage of disease: 21.0% of women with stage 4 disease and 30.6% of those with unknown died within two months of diagnosis, versus 9.6% of those diagnosed with stage 3 disease. Compared to patients diagnosed at stage 1-3, women with unknown stage were 9.5 times more likely to die within two months of diagnosis following adjustment for confounding factors.
- Burden of comorbidity: 34.9% of women with a score >2 died within two months of diagnosis, and 11.9% of those assigned a score of 0. Logistic regression models reported odds of mortality within two months that were 60% higher for women with a greater burden of comorbidities (34.9% of woman with a Charlson score of more score >2 than women with a score of 0.
- Women living in areas with more deprived socioeconomic status: 16.2% of women in the most deprived quintile died within two months, versus 12.0% in the least deprived quintile, or 50% more likely to die within two months following adjustment for confounders.

Alongside these was the impact of route to diagnosis. As shown in Figure 8, mortality rates were highest in ovarian cancer patients who were diagnosed via an emergency presentation, with

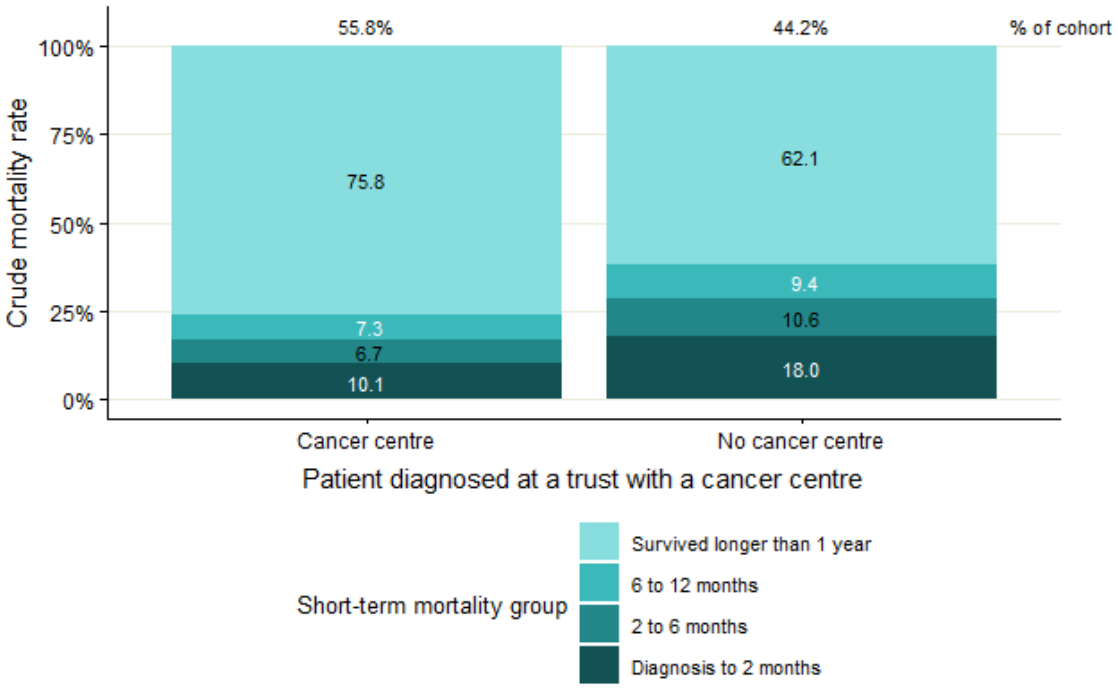
30.8% having died within 2 months of diagnosis. By contrast, women diagnosed via the Two Week Wait referral system showed the lowest mortality rate within two months of diagnosis (4.6%). Patients diagnosed via a non-urgent GP referral generally had higher mortality as these patients may experience longer delays in diagnosis, allowing the disease more time to progress, leading to poorer survival. Differences remained following adjustment for confounding factors, whereby patients diagnosed via emergency presentation were 4.3 times more likely to die within the first two months following diagnosis than women diagnosed via a Two Week Wait route.

Figure 8 Short-tern mortality in patients diagnosed with ovary, fallopian tube or primary peritoneal carcinomas by route to diagnosis, 2013 to 2018



There was also a trend observed of higher short-term mortality rates in patients diagnosed in an NHS secondary care trust that did not house a specialist gynaecological cancer centre compared to trusts that did (Figure 9). Following adjustment, differences were statistically significant only for the odds of short-term mortality between two and six months following diagnosis.

Figure 9 Short-tern mortality in patients diagnosed with ovary, fallopian tube or primary peritoneal carcinomas by whether the trust at diagnosis had a specialist gynaecological cancer centre, 2013 to 2018



Crude and case-mix adjusted results indicate variation in short-term mortality at a Cancer Alliance level, but to a lesser extent than the variation seen in survival and treatment analyses. The short-term mortality analyses corrected for route to diagnosis, which was not included in the models for the survival or treatment analyses. This may explain the diminution of Cancer Alliance variation. As with the survival and treatment analyses, it is likely that variation present at a more local level has been lost by aggregation of data at a Cancer Alliance level.

Radicality of ovarian, fallopian tube and primary peritoneal cancer surgery in England

Objective

A population-based analysis[5] of survival outcomes from 11 gynaecological cancer centres with known surgical ethos demonstrated extensive variation in surgical practice and association with differences in patient survival.

The surgical analysis phase of the OCAFP project therefore proposed to utilise routinely collected HES APC data to derive estimates of surgical radicality within gynaecological cancer centres at a hospital episode level, elucidating the extent to which extensive, ultra-radical surgery was offered in England. Additionally, the project sought to investigate whether surgical radicality was associated with survival.

In advance of this project, a list of recommended OPCS-4 surgical procedure codes was regularly circulated to the BGCS membership, who were in turn encouraged to disseminate the list to coding staff within hospital trusts to harmonise surgical data capture and submission. It was envisaged that the promotion of an agreed set of codes would permit a robust nationwide analysis that could be performed with rigour.

Method

Selecting surgical procedures

To validate the coding within HES, a list of codes for all distinct procedures recorded during the first nine months following diagnosis was extracted for a sample cohort of over 13,000 ovarian cancer patients (excluding borderline cases) diagnosed 2017 to 2018.

The resulting list of more than 1,000 procedure codes was then manually audited by three surgical gynaecological oncologists to identify entries of relevance to the surgical treatment of ovarian cancer. A total of 51 such codes were identified, representing 95% of all distinct surgical procedures captured.

Applying a modified Aletti scoring system

Each of the 51 procedure codes was assigned a score between one and three, as determined by consensus by the three clinicians (Appendix 1). Higher values indicated greater radicality. Each procedure was also allocated to a distinct category of surgery, which denoted the type of operation undertaken.

Although relevant to the surgical treatment of ovarian cancer, descriptions for three of the 51 selected procedures were deemed by the clinicians to be of insufficient detail to determine radicality. In these circumstances, two scores were assigned to each of the three procedures with the aim of reflecting the minimum or maximum probable level of radicality given the description available.

Scores were then summed at a hospital episode level, with each episode categorised as being of low (<4), intermediate (4-7) or high (≥8) complexity. When summing scores within each episode, to avoid a false impression of increased radicality from separate coding of routine elements of hysterectomy and salpingo-oophorectomy surgery, a maximum of one procedure was considered for codes denoting the following procedure categories: “hysterectomy”, “salpingectomy”, “TH-BSO, USO or BSO”.

This categorisation was undertaken twice, selecting either the minimum or maximum scores assigned by clinicians to each of the 51 procedures of interest, yielding two sets of results within which the ‘true’ level of surgical radicality should be situated.

It was envisaged that an analysis of these codes and their accompanying scores would provide an accurate summary of the radicality of surgical episodes.

Validation exercise

To confirm that the correct codes were selected and that the assigned scores were appropriate, a validation exercise was undertaken. This involved extracting episode-level procedure data from HES APC for one sample cancer centre in England. These events and their corresponding scores were then linked to detailed local hospital data that comprehensively described the actual procedures undertaken.

Two gynaecological oncology consultants audited these data and found poor concordance between HES APC and local hospital data, with discrepancies observed for more than 10% of patients. This prevented rigorous validation of the proposed method.

As the code list included those recommended for use by the BGCS and captured more than 95% of all procedure events in HES APC for a sample ovarian cohort, this discrepancy was hypothesised to be a consequence of incomplete local clinical coding to populate the institution’s HES records.

Further validation and refinement to check this hypothesis required more resource than was available to the OCAFP, needing validation within other cancer centres to determine whether coding discrepancies were localised or widespread, and in which ways coding practices could be improved.

Limitations

The OCAFP was not funded to validate surgical radicality scores within centres and directly advise on improvements to coding practice. It is clear from the work undertaken that any analysis of surgical radicality using nationally collected surgical data in HES APC should include a validation exercise such that radicality can be robustly defined. In the absence of such interrogation, there is a high likelihood that derived radicalities will be unreliable.

Nevertheless, the question of variation in surgical practice across England and its association with cancer survival remains an extremely important and unaddressed question. Our recommendation for the forthcoming nationally funded national ovarian cancer audit is to identify a set of cancer centres which will be willing to work with the national audit to share granular local data, such that a method of radicality scoring of routinely captured HES and cancer registration data can be refined. Moreover, to improve and standardise the submission of surgical data to routine data sources.

Impact and learnings

Challenges

The outputs planned by the OCAFP were subject to a series of data-related challenges. By no means comprehensive, the list below highlights some of the main data challenges faced during the OCAFP.

- Data completeness: across successive projects, poor data completeness on key data items was likely to have impacted the interpretation of results.
    - Performance status: As noted earlier in the report, separate efforts were undertaken to isolate the effect of geographic variations in clinical practice on the treatment pathway and short-term mortality. To do so reliably requires adjustment for all factors which were associated with these outcomes and that may have been distributed unevenly between geographies. However, data completeness of performance status at diagnosis was particularly poor, negating its inclusion into the adjustment model. Presented estimates of geographic variation are therefore subject to residual confounding, and this should be borne in mind during interpretation.
    - Comorbidities: Multivariable-adjusted models account for differences in patient comorbidity via adjustment for their Charlson comorbidity index, which assigns scores to a series of pre-defined comorbid conditions recorded during hospital admissions. Although this variable had high completeness, the ability to identify comorbid conditions was dependent solely on recording within the inpatient setting, potentially biasing scores downward in instances where conditions were predominantly managed and documented in a primary care rather than a secondary care setting. Due to the lack of sensitivity of this methodology in capturing comorbidity, almost four-fifths of patients in some reports were scored as presenting without comorbidity – a figure at odds with the age profile of ovarian cancer patients in England and population-based research publications elsewhere.
    - Residual disease: The proposed study into the radicality of ovarian cancer surgery was intended to include an assessment of its impact on residual disease – the amount of cancer tissue that remains following surgery. A data item exists in the Cancer Outcomes and Services Dataset (COSD) for the capture of this information. However, despite extensive efforts to liaise with the clinical community to improve reporting over successive years, very low completeness on this data item precluded its analysis within the project.

- Data availability: alongside the issue of data completeness, the OCAFP was challenged by the lack of data availability for certain data items of interest.
    - Route to diagnosis: The route to diagnosis can be an important determinant of a patient's treatment pathway, with individuals who present in an emergency setting likely exhibiting more advanced disease than those referred for assessment as suspected cancer cases for from primary care. Unfortunately, adjustment for this important factor was not possible for some of the OCAFP analyses as the data item was unavailable for all years of diagnosis.
    - Timely cancer registration: Due to the impact of the Covid-19 pandemic on cancer registration, reports produced as part of the OCAFP have a greater lag that would typically have been the case between the most recent year of included diagnoses and the date of publication.

- Data accuracy.
    - The OCAFP was not funded in the manner of a national audit to include resources for data cleaning and pursuit of missing data items. The project was therefore reliant on the accuracy of routinely captured data. The feasibility aspect of the project included an assessment where possible of the validity of the data, which were all captured through existing processes during routine management of ovarian cancer cases in England. The project to assess surgical radicality highlighted a lack of data accuracy for HES surgical procedure coding. Whilst there is generally more scrutiny and oversight of routine cancer registration data capture which formed the basis of the profile, treatment and short-term mortality reports, hidden data inaccuracies may have also impacted the analyses published in these reports.

New data

The OCAFP resulted in the release of new ovarian cancer data that:

- Provides a more accurate and up-to-date picture of ovarian cancer diagnosis and survival than had been available previously.
- Demonstrated statistically significant geographical variation in ovarian cancer treatment.
- Brought attention to previously unknown inequalities, such as higher rates of short-term mortality according to factors like deprivation and whether diagnosis occurred at a hospital housing a specialist gynaecological cancer centre.

The Future

Disease Profile and Treatment Analyses update

The final phase of the OCAFP will be the publication of updated incidence, mortality, survival and treatment analyses involving cases registered between 2015–2019. Treatment data for patients diagnosed in 2019 will help demonstrate whether surgical treatment rates improved during the period in which the clinical community was involved in the OCAFP project and provide an insight into evolving changes in the geographical variation demonstrated in the Treatment Report. It is expected that the fuller impact of the pandemic on cancer diagnosis and treatment will be captured in the forthcoming national ovarian cancer audit, which will analyse cases diagnosed and further analysis of treatments administered during 2020 onwards.

Securing a long-term audit

In May 2021 the HQIP announced that it would be commissioning five new cancer audits for England and Wales, to be delivered through a National Cancer Audit Collaborating Centre. This includes ovarian cancer, meaning the OCAFP had achieved its goal of demonstrating the benefit of, and making the case for, a nationally funded ovarian cancer audit.

Clinical practice

The provision of more granular data at provider level via CancerStats2 enabled individual providers to use it to explore and challenge practice within their geography, with teams who exhibited low surgery rates reviewing pathways to search for factors which can be addressed to improve access to surgery for an increased proportion of patients. Examples of local impact are provided in Appendix 2, which lists comments from consultants across England.

The demonstration of lower surgery rates for patients diagnosed in trusts which do not house a specialist gynaecological cancer centre has particularly focused attention on the management of women diagnosed in these hospitals through the emergency presentation pathway. A number of Cancer Centres have used data from the OCAFP reports to demonstrate need and access grant funding for service transformation research to optimise clinical pathways. Publication of updated data in the final OCAFP report and the forthcoming national ovarian cancer audit will support further and more detailed work on clinical pathways to optimise surgery and chemotherapy treatment rates.

Based on the outcomes of the OCAFP disease profile and treatment reports, the BGCS convened a multidisciplinary group to devise quality performance indicators (QPIs) that set minimum and optimum standards for cancer care providers. The OCAFP data was crucial in establishing real-world benchmarking standards which have been demonstrated to be achievable in highly performing Cancer Alliances. The QPIs[6] were agreed by the gynaecological cancer clinical community after a period of consultation with the BGCS membership, and represent the first data-driven, evidence-based QPIs for ovarian cancer in England.

In 2022, the Royal College of Obstetricians and Gynaecologists (RCOG) agreed that all cancer centres applying to accredit their hospitals for subspecialty training would need to demonstrate compliance with these QPIs as a condition for accreditation or reaccreditation. It is envisaged that the forthcoming national ovarian cancer audit will publish data against these QPIs.

Appendices

Appendix 1. Surgical procedures, codes and assigned scores

OPCS4	DESCRIPTION	CATEGORY	SCORE_MIN	SCORE_MAX	CONSTRAINT
T391	EXCISION OF LESION OF POSTERIOR PERITONEUM	ABDOMINAL PERITONEUM STRIPPING	1	1	
T171	EXCISION OF LESION OF DIAPHRAGM	DIAPHRAGM STRIPPING/RESECTION	2	2	
T178	OTHER SPECIFIED OTHER OPERATIONS ON DIAPHRAGM	DIAPHRAGM STRIPPING/RESECTION	2	2	
Q073	ABDOMINAL HYSTEROCOLPECTOMY NEC	HYSTERECTOMY	1	1	Only a maximum of one such procedure to be counted per episode.
Q079	UNSPECIFIED ABDOMINAL EXCISION OF UTERUS	HYSTERECTOMY	1	1	
Q082	VAGINAL HYSTERECTOMY AND EXCISION OF PERIUTERINE TISSUE NEC	HYSTERECTOMY	1	1	
H059	UNSPECIFIED TOTAL EXCISION OF COLON	LARGE BOWEL RESECTION	2	3	
H074	RIGHT HEMICOLECTOMY AND ILEOSTOMY HFQ	LARGE BOWEL RESECTION	2	2	If H152 also recorded within the episode, then a maximum score of 2.
H105	SIGMOID COLECTOMY AND EXTERIORISATION OF BOWEL NEC	LARGE BOWEL RESECTION	2	2	
H335	RECTOSIGMOIDECTOMY AND CLOSURE OF RECTAL STUMP AND EXTERIORISATION OF BOWEL	LARGE BOWEL RESECTION	2	2	
H336	ANTERIOR RESECTION OF RECTUM AND EXTERIORISATION OF BOWEL	LARGE BOWEL RESECTION	2	2	
X143	POSTERIOR EXENTERATION OF PELVIS	LARGE BOWEL RESECTION	2	3	
H062	EXTENDED RIGHT HEMICOLECTOMY AND ANASTOMOSIS OF ILEUM TO COLON	LARGE BOWEL RESECTION AND ANASTOMOSES	3	3	
H071	RIGHT HEMICOLECTOMY AND END TO END ANASTOMOSIS OF ILEUM TO COLON	LARGE BOWEL RESECTION AND ANASTOMOSES	3	3	
H073	RIGHT HEMICOLECTOMY AND ANASTOMOSIS NEC	LARGE BOWEL RESECTION AND ANASTOMOSES	3	3	
H081	TRANSVERSE COLECTOMY AND END TO END ANASTOMOSIS	LARGE BOWEL RESECTION AND ANASTOMOSES	3	3	
H083	TRANSVERSE COLECTOMY AND ANASTOMOSIS NEC	LARGE BOWEL RESECTION AND ANASTOMOSES	3	3	
H091	LEFT HEMICOLECTOMY AND END TO END ANASTOMOSIS OF COLON TO RECTUM	LARGE BOWEL RESECTION AND ANASTOMOSES	3	3	
H095	LEFT HEMICOLECTOMY AND EXTERIORISATION OF BOWEL NEC	LARGE BOWEL RESECTION AND ANASTOMOSES	2	2	

H101	SIGMOID COLECTOMY AND END TO END ANASTOMOSIS OF ILEUM TO RECTUM	LARGE BOWEL RESECTION AND ANASTOMOSES	3	3	
H102	SIGMOID COLECTOMY AND ANASTOMOSIS OF COLON TO RECTUM	LARGE BOWEL RESECTION AND ANASTOMOSES	3	3	
H103	SIGMOID COLECTOMY AND ANASTOMOSIS NEC	LARGE BOWEL RESECTION AND ANASTOMOSES	3	3	
J031	EXCISION OF LESION OF LIVER NEC	LIVER RESECTION	2	2	
T361	OMENTECTOMY	OMENTECTOMY	1	1	
T362	EXCISION OF LESION OF OMENTUM	OMENTECTOMY	1	1	
T854	BLOCK DISSECTION OF PARA-AORTIC LYMPH NODES	PARA-AORTIC LYMPHADENECTOMY	2	2	
T866	SAMPLING OF PARA-AORTIC LYMPH NODES	PARA-AORTIC LYMPHADENECTOMY	1	1	
T875	EXCISION OR BIOPSY OF PARA-AORTIC LYMPH NODE	PARA-AORTIC LYMPHADENECTOMY	1	1	
T876	EXCISION OR BIOPSY OF PORTA HEPATIS LYMPH NODE	PARA-AORTIC LYMPHADENECTOMY	2	3	
T856	BLOCK DISSECTION OF PELVIC LYMPH NODES	PELVIC LYMPHADENECTOMY	1	1	
T858	OTHER SPECIFIED BLOCK DISSECTION OF LYMPH NODES	PELVIC LYMPHADENECTOMY	1	1	
H333	ANTERIOR RESECTION OF RECTUM AND ANASTOMOSIS OF COLON TO RECTUM USING STAPLES	RECTOSIGMOIDECTOMY AND ANASTOMOSIS	3	3	
H334	ANTERIOR RESECTION OF RECTUM AND ANASTOMOSIS NEC	RECTOSIGMOIDECTOMY AND ANASTOMOSIS	3	3	
G693	ILEECTOMY AND ANASTOMOSIS OF ILEUM TO ILEUM	SMALL BOWEL RESECTION	1	1	
G694	ILEECTOMY AND ANASTOMOSIS OF ILEUM TO COLON	SMALL BOWEL RESECTION	2	2	
J692	TOTAL SPLENECTOMY	SPLENECTOMY	2	2	Only a maximum of one such procedure to be counted per episode.
J699	UNSPECIFIED TOTAL EXCISION OF SPLEEN	SPLENECTOMY	2	2	
J708	OTHER SPECIFIED OTHER EXCISION OF SPLEEN	SPLENECTOMY	2	2	
Q071	ABDOMINAL HYSTEROCOLPECTOMY AND EXCISION OF PERIUTERINE TISSUE	TH-BSO OR USO OR BSO	1	1	
Q072	ABDOMINAL EXCISION OF UTERUS	TH-BSO OR USO OR BSO	1	1	
Q074	TOTAL ABDOMINAL HYSTERECTOMY NEC	TH-BSO OR USO OR BSO	1	1	
Q075	SUBTOTAL ABDOMINAL HYSTERECTOMY	TH-BSO OR USO OR BSO	1	1	Only a maximum of one such procedure to be counted per episode.
Q088	OTHER SPECIFIED VAGINAL EXCISION OF UTERUS	TH-BSO OR USO OR BSO	1	1	
Q089	UNSPECIFIED VAGINAL EXCISION OF UTERUS	TH-BSO OR USO OR BSO	1	1	
Q221	BILATERAL SALPINGOOPHORECTOMY	TH-BSO OR USO OR BSO	1	1	
Q223	BILATERAL OOPHORECTOMY NEC	TH-BSO OR USO OR BSO	1	1	
Q231	UNILATERAL SALPINGOOPHORECTOMY NEC	TH-BSO OR USO OR BSO	1	1	

Q232	SALPINGOOPHORECTOMY OF REMAINING SOLITARY FALLOPIAN TUBE AND OVARY	TH-BSO OR USO OR BSO	1	1
Q235	UNILATERAL OOPHORECTOMY NEC	TH-BSO OR USO OR BSO	1	1
Q236	OOPHORECTOMY OF REMAINING SOLITARY OVARY NEC	TH-BSO OR USO OR BSO	1	1
Q241	SALPINGOOPHORECTOMY NEC	TH-BSO OR USO OR BSO	1	1
Q243	OOPHORECTOMY NEC	TH-BSO OR USO OR BSO	1	1

TH-BSO OR USO OR BSO: total hysterectomy (TH) and bilateral salpingo-oophorectomy (BSO), or unilateral salpingo-oophorectomy (USO) or BSO.

Appendix 2. Comments on impact from the BCGS membership

Consultant in Leicester

In Leicester and since the results of this Audit we have:

1) Supported our subspecialty trainee to go for a fellowship in Basingstoke and he is currently working as a consultant in Leicester and since then we have significantly increased our cytoreductive surgery rate, and our complete cytoreduction rate. We have moved towards an independent Gynaecological Oncology approach in ultra-staging procedures which has allowed us to:

- Offer CRS to more patients safely and in timely manner.
- Improved our Complete cytoreduction rate.
- We are establishing buddy operating system in our department, as these surgeries can be challenging at times.
- Our new approach so far is progressing well with no significant complications, and very low stoma rate. We are currently auditing our data since this new approach with the aim to be presented very soon.

2) We have taken part in the establishment of a regional MDT lead by ECAG to discuss any ovarian cases in the region that seemed to be not suitable for any treatment at the local MDT level.

I strongly believe that this audit has provided us in Leicester and East midland as a region with a great insight on our performance and areas for improvement.

Consultant in Derby

As we have already discussed before, following the publication of the Ovarian Cancer Feasibility Pilot report, East Midlands Cancer Alliance have funded a Ovarian Cancer East Midlands Regional MDT which is due to start in March 2023.

This is mainly aimed for discussion of ovarian cancer cases that do not have the standard management of Chemotherapy and Surgery or are not offered any treatment. This discussion will be held at Regional level and is collaborative approach with input from all four Cancer centres in East Midlands.

We aim to reduce variation in treatment across East Midlands and hopefully improve survival in the long term

Consultant in West Midlands

The feasibility project has been used to drive the work of the West Midlands Gynaecological Oncology Operational Delivery Network.

Consultant in Bath

We have used this to drive the quality of the data recording in our MDT which has subsequently dramatically improved. Once data recording is consistent we can use it to benchmark improvements.

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