NHS

Trent Cancer Registry

Quality and Completion of Gynaecological Cancer Data in the National Cancer Data Repository

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Contents

Executive Summary

- Once duplicate, 'out-of-region' cases (where cases are registered by both the registry of residence and by the registry within whose area they are treated) are removed, the number of gynaecological cancer cases recorded in the National Cancer Data Repository (NCDR) closely matches the number in the UK Cancer Information Systems (UKCIS).

- A valid ethnicity code is available for over 80% of cervical, uterine and ovarian patients, diagnosed in 2006-2008, in the NCDR.

- A Charlson Co-morbidity Score is available for over 80% of cervical, uterine and ovarian patients, diagnosed in 2006-2008, in the NCDR.

- In total, there are less than 2% of cases where the only diagnosis information was from a death certificate only (DCO). However, NWCIS and WMCIU have around 5% of ovarian cancer cases as a DCO.

- The completion of cervical screening status varies between registries; ranging from no information submitted for Thames to 95% of cases with a valid screening status available for NYCRIS. Overall, in recent years, around a third of cervical cancer cases in women of screening age have screening status recorded.

- In recent years, the majority of registries have over 70% of cervical cancer cases staged using FIGO. Completeness of FIGO stage is lower for uterine and ovarian cancers, but in recent years rates have improved, with ECRIC and WMCIU having over 80% of patients with a FIGO stage for these two cancers.

- There is some notable variation in the stage profile of registries. This may reflect differences in practices rather than real differences in the stage of disease at diagnosis. Therefore, caution should currently be taken when analysing the stage data within the NCDR.

- Other staging information, such as tumour extent, nodal status and metastatic status, is not consistently available from registries for any of the gynaecological sites.

- There is some variation across registries in the proportion of cases flagged as receiving treatment. This, in part, reflects different processes between registries in the coding of treatment rather than real differences in the treatment rates. Caution should therefore be taken when analysing the treatment information in the NCDR.

Introduction

Trent Cancer Registry is the lead registry in England for gynaecological cancers. The National Cancer Data Repository (NCDR) is one of the main sources of data used in the production of national and sub-national incidence, mortality, survival and treatment information for gynaecological cancers. The NCDR merges all of the eight English cancer registries' data, compiling all cancer registrations from 1990 to 2008. Additional data sources such as the Hospital Episodes Statistics (HES), National Clinical Audit data and ONS data are also combined with each record, providing a comprehensive set of details for each tumour record.

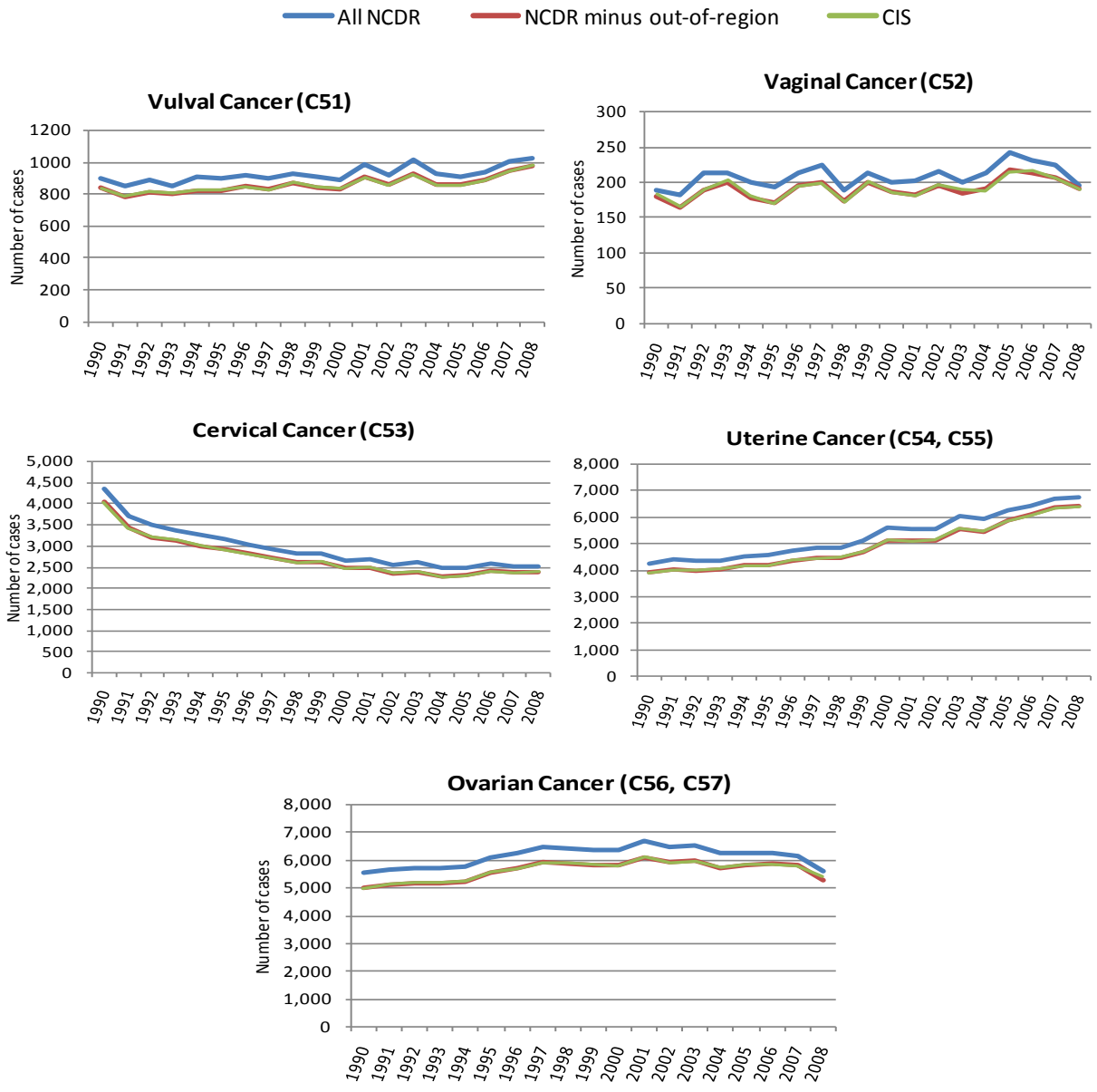
The purpose of this report is to assess the quality of key data items available in the NCDR, to allow an understanding of how the data may be used at national level. This will provide a useful reference to those wanting to understand the scope of the NCDR in relation to specific projects; whilst also influencing improvements in the collection of gynaecological data, not only in the compilation of the NCDR, but also at registry level.

The report includes information on invasive cancers, (ICD 10 C51 to C57; cancers of the vulva, vagina, cervix uteri, uterus, ovaries and other unspecified parts). Cancer of the placenta (C58) is extremely rare and there are only 158 cases in the whole database; this site is not considered in this report. In situ gynaecological cancers are also not considered, the ascertainment of these, particularly for cervical cancers, is already known to be suboptimal across the country and a separate assessment of these is underway. For the majority of the data items only cervical, uterine and ovarian cancers are considered, these being the most common cancers and those for which data are most commonly analysed.

For the majority of data items the years 2006-2008 only are analysed, these being the most relevant in reflecting current practice across registries. The report also analyses data items available in the derived NCDR dataset received on the 12th April 2011. This dataset provided updated death details from the ONS annual death dataset, updated ethnicity information and derived Charlson Score from HES data. This was combined with the 2008 NCDR dataset.

Incidence

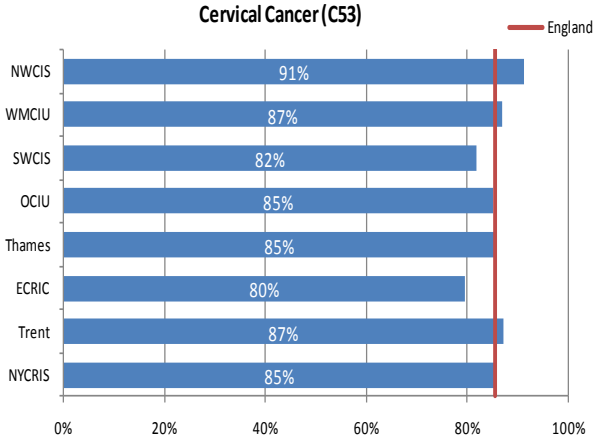
The following trend charts compare the number of cases each year in the NCDR with the number of cases in another national dataset, the UK Cancer Information System (UKCIS). The UKCIS provides incidence, mortality and survival figures; the underlying data is a cleaned subset of data submitted by registries. The NCDR compiles all registrations submitted by the registries. This includes "out-of-region" patients who may be recorded by two registries (the registry of "residence" and the registry of "treatment"). The rationale behind maintaining all records is to ensure that information is not lost; duplicates may have different information available. The charts below show the importance of being able to identify and discount the cases which may be duplicated by another registry. The out-of-region patients were identified using the extra regional flag in the NCDR. The analysis shows that, once out-of-region cases have been identified, there is strong agreement between the incidence of gynaecological cancers in the NCDR when compared to the CIS. Exploring Issues surrounding ascertainment, which may affect all data sources, are beyond the scope of this report.

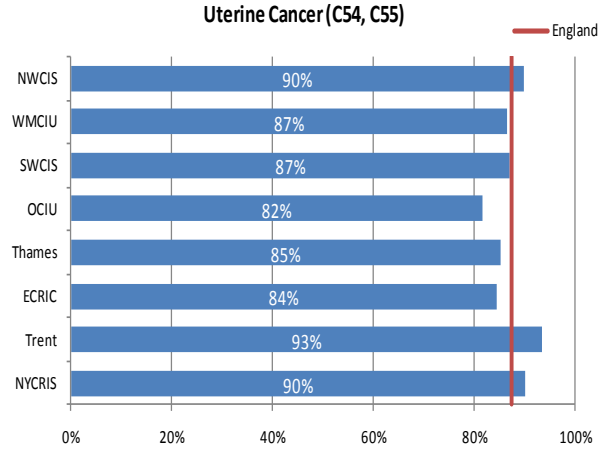


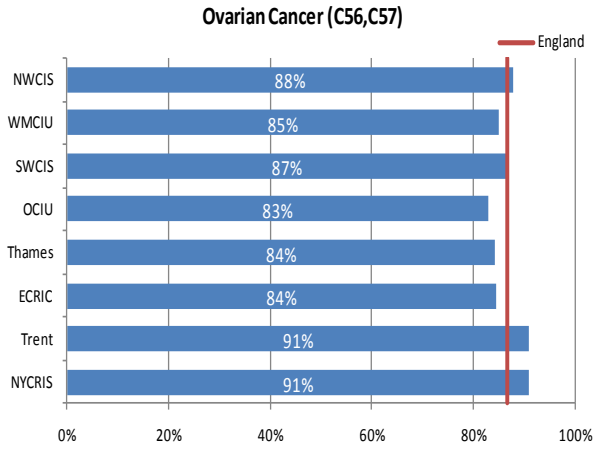
Patient Details

Ethnicity

The ethnicity data is available in the registry data submitted for the NCDR. However, additional data has also been added using updated HES data from the derived dataset accompanying the NCDR. The charts show the proportion of cases in 2006-2008 that have a valid ethnicity code i.e. a code indicating anything other than 'not available' or 'unknown'. Combining the sources of ethnicity data provides 80% or more of cases with ethnicity information across the registries. In more than 99% of cases where there was both a valid ethnicity code in the NCDR and in the updated HES derived dataset, the same broad ethnicity group was coded to each record.

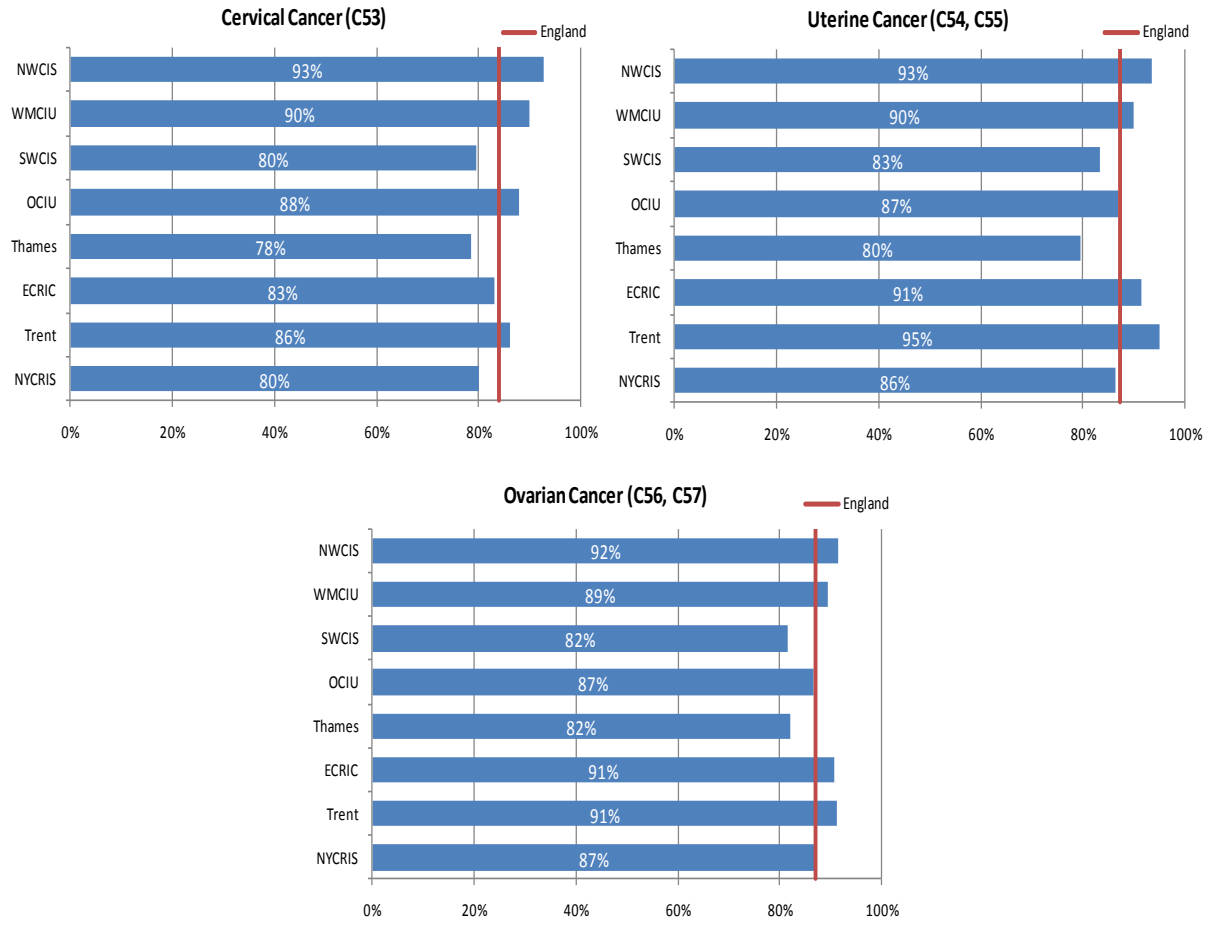






Charlson Score

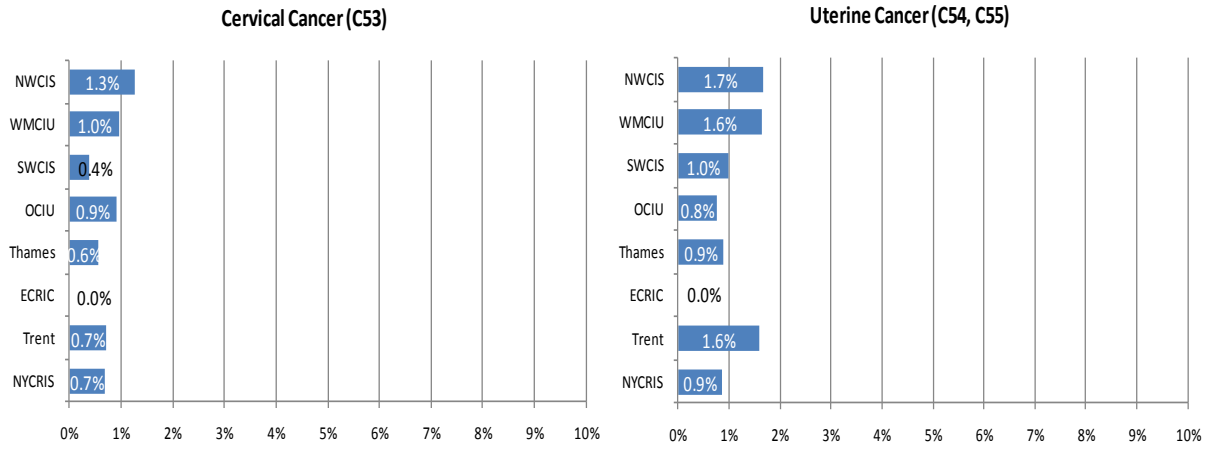
The Charlson Score is the co-morbidities measure created, where available, from the in-patient HES data for each record in the NCDR. It takes into consideration all in-patient activity occurring two years prior and 3 months after diagnosis for each patient. A score is then assigned for each mention of a relevant condition (see table 2 in appendix). This methodology is currently under review. The charts below present the proportion of cases in 2006-2008 where a combined Charlson Score is available in the derived data for the NCDR. There is some variation across registries; however for all registries, a Charlson Score is available for 78% or more of cases for the three gynaecological cancers.

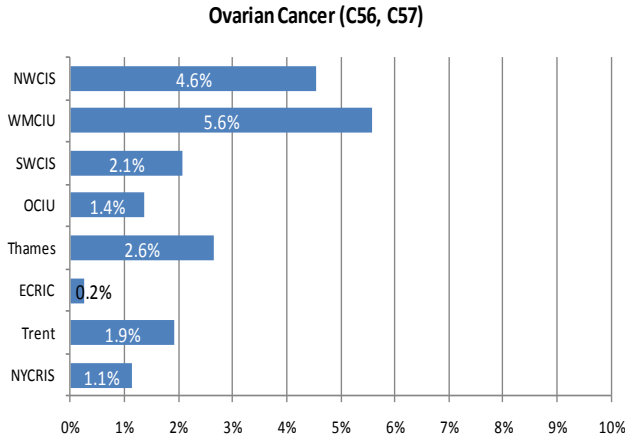


Diagnosis Information

Death Certificate Only (DCO) Registrations

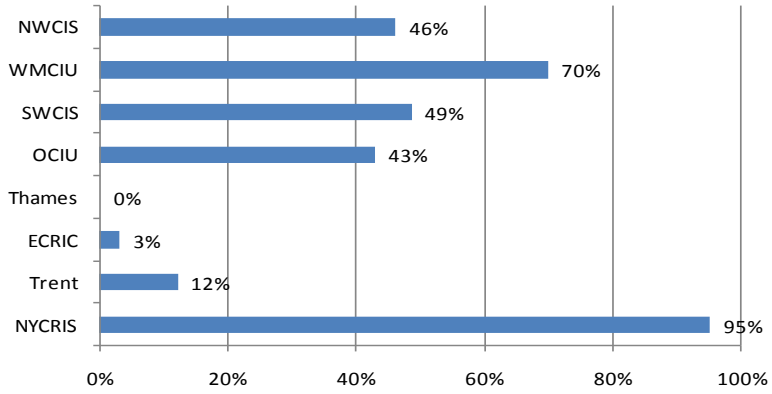
The way in which a cancer diagnosis is made is an important indication of the robustness of that diagnosis and the information relating to the patient. DCO registrations have only a death certificate indicating that a cancer diagnosis has been made and contain no detailed information about the tumour or treatment. Registries follow up any DCOs in an attempt to gain further information regarding the diagnosis. For many registries the proportion of DCOs in 2006-2008 for each gynaecological site is 2% or less. However, NWCIS and WMCIU have around 5% of ovarian cancer cases with a basis of diagnosis as DCO. Thames also has a higher proportion of ovarian DCOs with 3% of cases as such. ECRIC only have DCO cases for diagnoses of ovarian cancer.



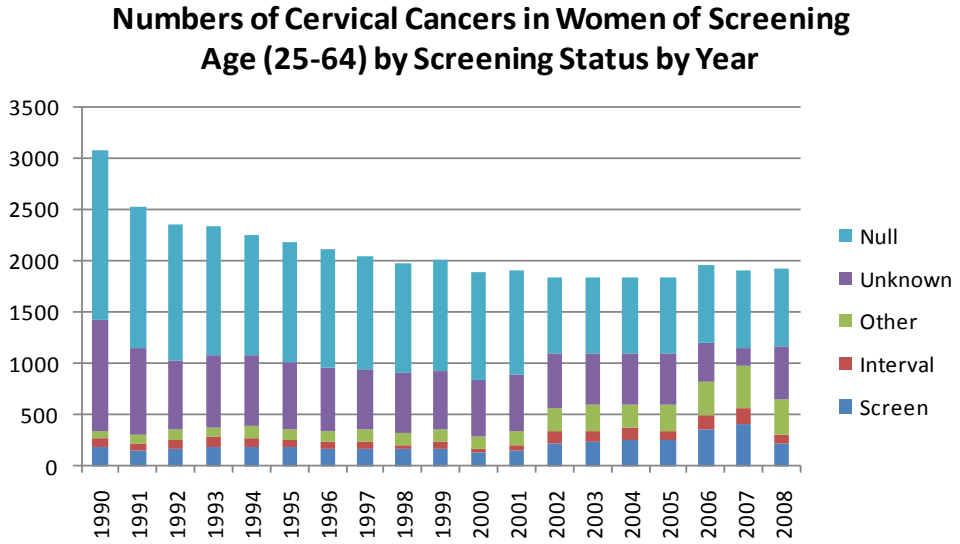


Screening Status– cervical cancer only

The screening status information is collected by the registries from the Quality Assurance Reference Centres (QARC). It indicates when, in relation to the patients screening history, the diagnosis of cervical cancer was made. The NCDR groups this into four broader categories: a cancer detected at screening; a cancer detected in between screening (interval cancer); other cancers, which include those who are lapsed attendees, non-attendees, lost to follow-up or cancers in those who are uninvited or under/over the screening age; and unknown screening status. The chart below shows the proportion of cases where a screening status other than 'unknown' is available for 2006-2008. The completion of screening status varies across the registries. Thames has no submitted information and NYCRIS has 95% with a valid screening status available. The figures are the proportion of all cases and not only those within screening age.



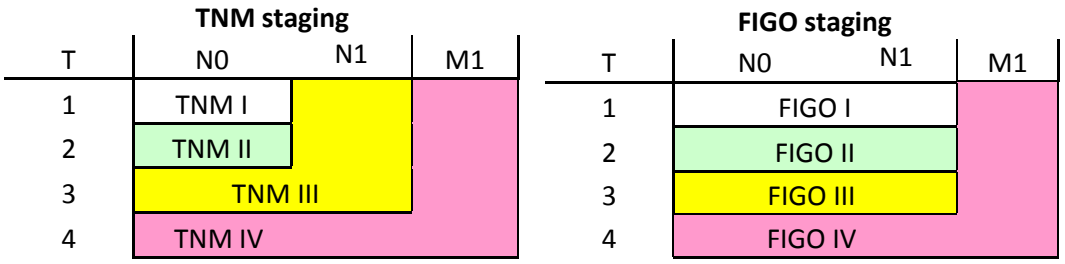
The chart below shows the trend in the proportion of cases in the NCDR that fall into each of the screening status categories. The cases included have been restricted to women of screening age, 25-64. The proportion of null and unknown screening status has fallen from 89% in 1990 to just over two thirds of all cervical cancers in women of screening age in 2008.



Staging Information

FIGO versus TNM

FIGO stage is the most complete system of stage information available in the NCDR; this being the recommended staging system for gynaecological cancers. However, some registries submitted both FIGO and TNM stage. For both ovarian and uterine cancers the two staging systems directly correspond i.e. a FIGO stage I is comparable to a TNM stage I. For cervical cancer, there may be no comparability between the systems for stages I, II or III. This is because FIGO staging ignores nodal status for cervical cancer; a stage III TNM could also be recorded as a FIGO I, II or III. It is recommended that additional nodal status should be available for early cervical cancers that are surgically managed[1] however; at present there is a limited proportion of cervical cases with nodal status available in the NCDR (see the nodal status charts below).



[1]NCAT, Gynaecological Clinical Lines of Enquiry: Briefing Paper for National Cancer Peer Review. http://www.cquins.nhs.uk/?menu=resources

FIGO

The charts below show the trends in the proportion of cervical, uterine and ovarian cases for each registry. Alongside these are bar charts showing the proportion of each broad stage category by registry, for cases diagnosed in 2006-2008. Variation in the proportion of stage at diagnosis may reflect differences in the staging process or reflect real differences in the stage at which women present with disease in the different regions.

Caution must be taken when using stage information in the NCDR; national analysis of the data may not be possible due to the variable quality of stage across registries. Historically, registries have only been performance managed on the level of completeness of cervical cancer staging, with a performance indicator (PI) benchmark of 70%. Other gynaecological cancer sites have varying levels of stage data available. This means that staging information for other gynaecological sites has not undergone the same rigorous quality assurance and therefore may not be as reliable as cervical stage data. For example, when compared to other registries prior to 2007, a higher proportion of ovarian cases registered by NYCRIS were recorded as stage IV disease, whilst from 2007 onwards proportions are comparable to other registries. NYCRIS has identified that a change took place in the way stage IV disease was derived from 2007 onwards. A review of these stage IV cases is to be undertaken in the future.

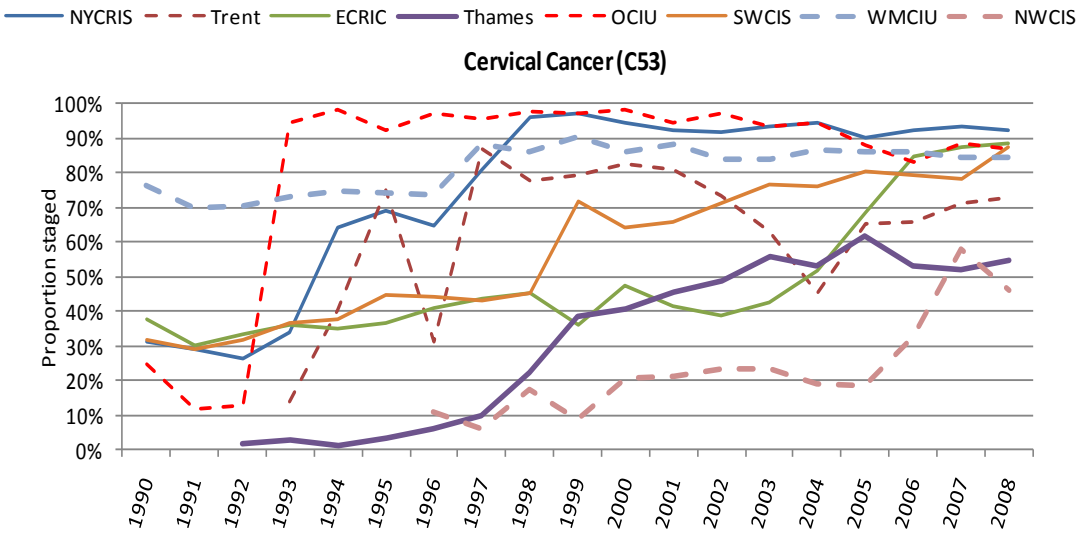
Cases registered by Thames are also notable; when compared to other registries there appears to be a much smaller proportion of stage I disease. Differences in the stage profile of a registry may be affected by differences in the source of information used to derive stage.

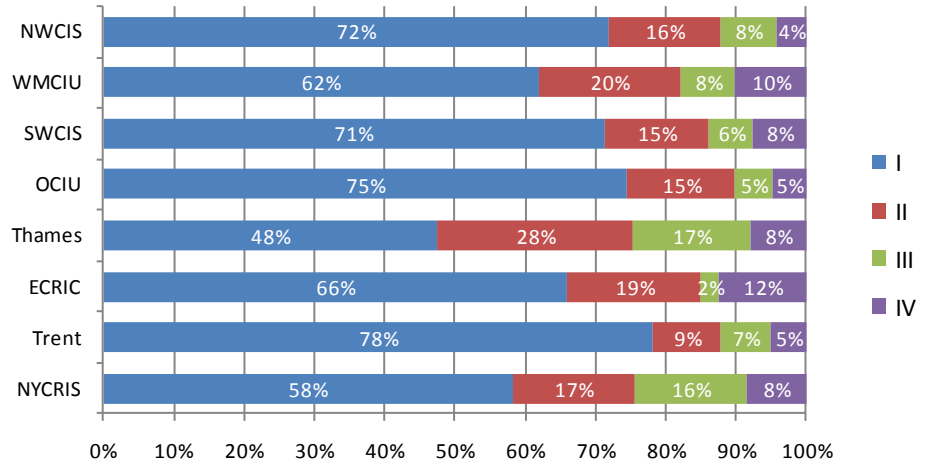
For uterine and ovarian cases registered at SWCIS there are lower proportions of stage IV disease when compared to other registries. However, when FIGO and TNM stage information are combined for 2006-2008, another 17% (482) of ovarian cases and another 2% (47) of uterine cases are assigned with stage IV disease.

Cervical Cancer

The proportion of FIGO staged cervical cases has increased over time for most registries. In 2007, over 50% of all cervical cases across the registries had a valid stage available. However, for NWCIS this has dropped to just below 50% in 2008. For NYCRIS, ECRIC, OCIU, SWCIS and WMCIU the completion of staging information is above 80% in the most recent years.

The second chart below shows that, between registries, there is some variation in stage profile. Thames are most notable, having a smaller proportion of cases with stage I disease at diagnosis, and higher proportions of stage II and III disease than other registries. ECRIC has the highest proportion of stage IV disease with around 12% of staged cases diagnosed as such. This may reflect different registration practices rather than real differences in the stage of disease at diagnosis.

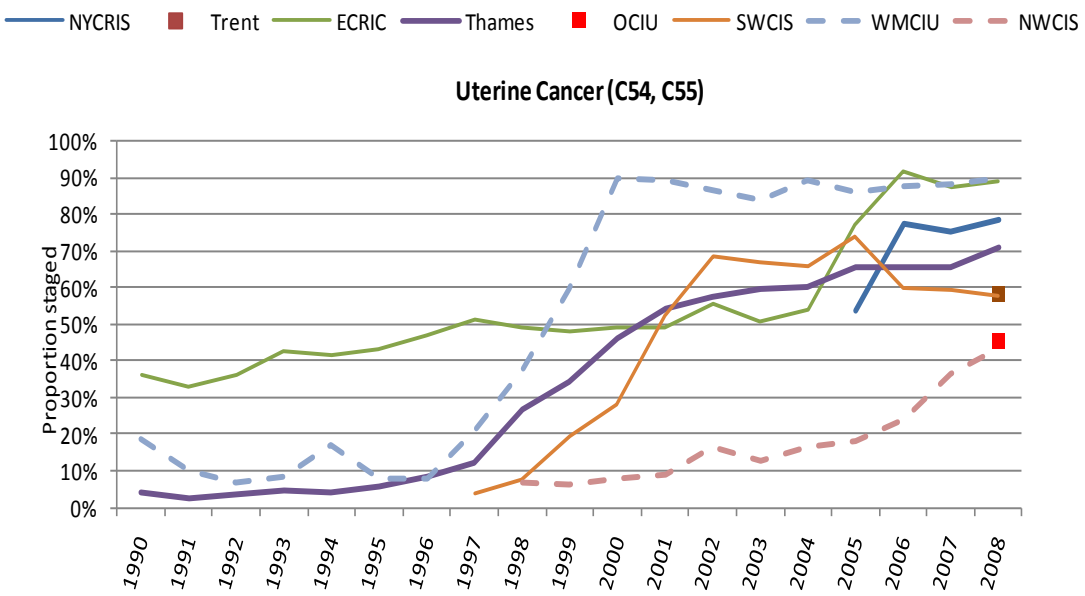


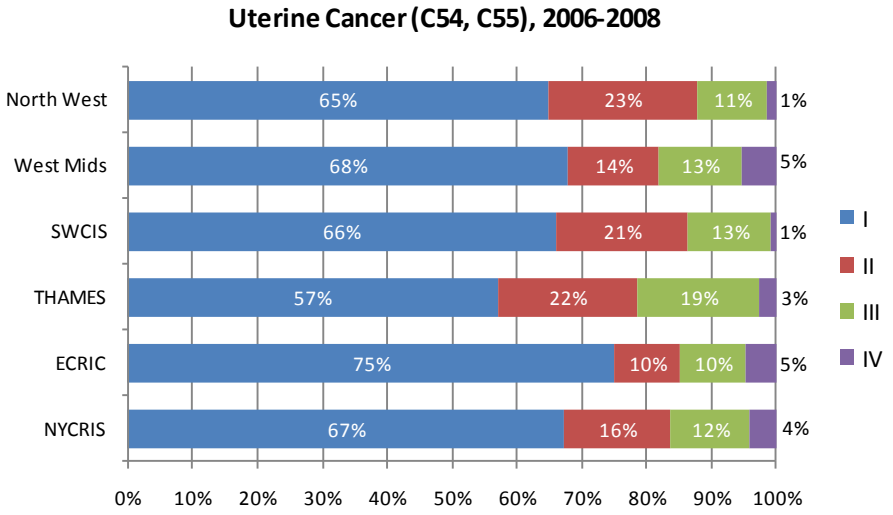


Uterine Cancer

The proportion of FIGO stage for uterine cancer has also increased over time. Two registries have a valid stage recorded for over 80% of uterine cancers; WMCIU since 2000 and ECRIC since 2006. OCIU and Trent only have stage data available for 2008 with 48% and 58%, respectively.

The second chart below shows that, between registries, there is some variation in stage profile. As for cervical cancer, Thames also has a lower proportion of uterine cases with stage I disease at diagnosis; all other registries have around 65-70% of cases with stage I disease.



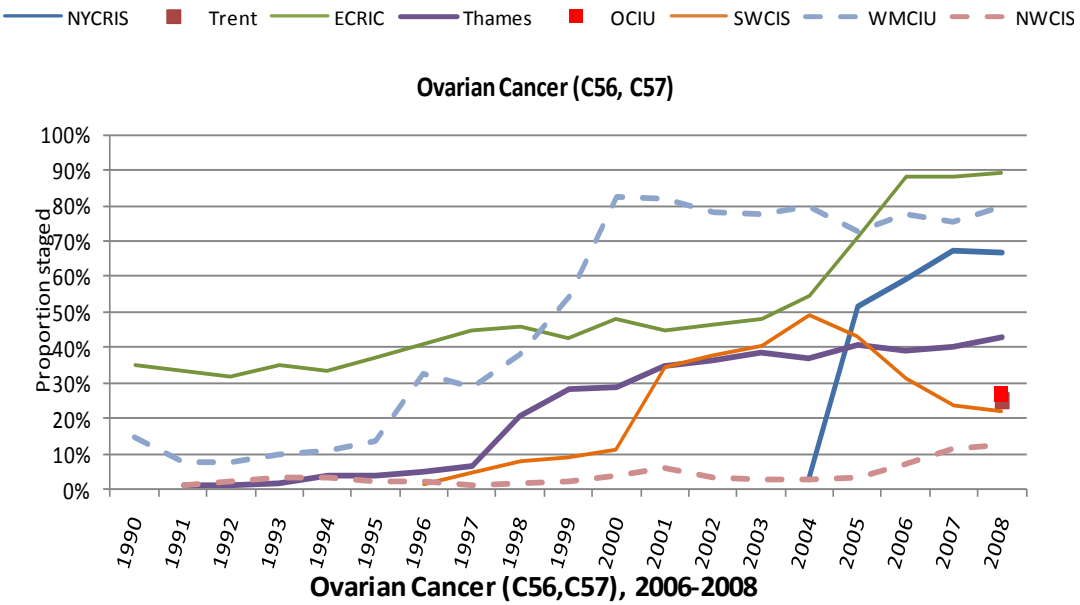


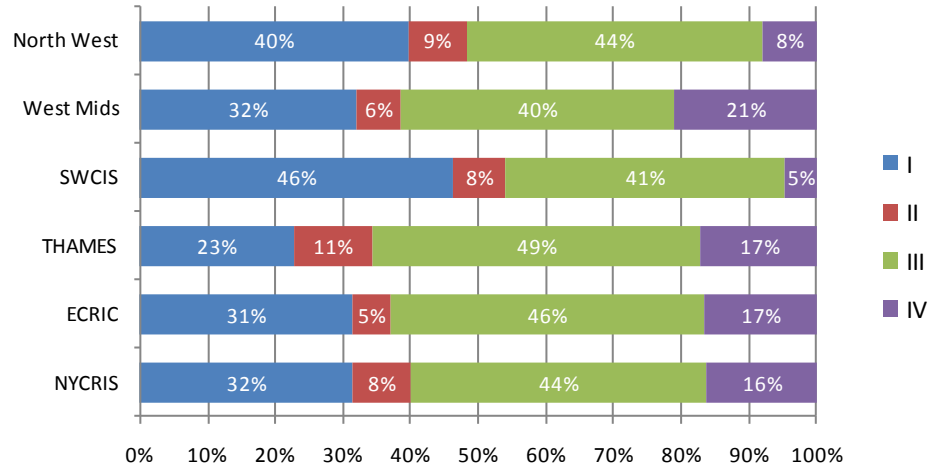
N.B Trent and Oxford are absent from this chart as they only have one year of data available.

Ovarian Cancer

The proportion of FIGO stage ovarian cases has increased over time. As for uterine cancer, ECRIC and WMCIU have the highest proportion of ovarian cases staged; ECRIC has almost 90% staged in the most recent three years and WMCIU has around 80% of cases staged since 2000. NYCRIS has around 70% of ovarian cases staged in the most recent years. All other registries have less than 50% of cases with staging information for all years. Trent and OCIU have around 25% of cases staged in 2008.

Stage I disease at diagnosis is much less common for women presenting with ovarian cancer than women presenting with cervical and uterine cancer. Again, Thames has a much lower proportion of stage I disease than other registries and a greater proportion of stage II and III disease, at around 11% and 49% of all staged ovarian cases, respectively. SWCIS has the highest proportion of stage I disease with over 40% of staged cases, and a much lower proportion of stage IV disease. However, when combining the TNM and FIGO stage information as discussed above, the stage profile for SWCIS is: 28% stage I, 5% stage 2, 25% stage 3 and 43% stage IV disease.



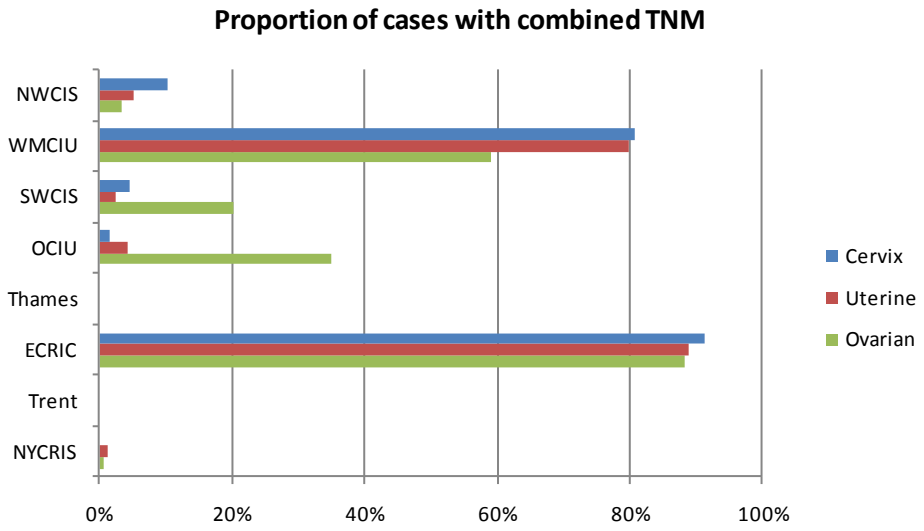


N.B Trent and Oxford are absent from this chart as they only have one year of data available.

TNM

In the NCDR there are various TNM variables which record stage; combined TNM stage which is derived using clinical or pathological methods, an integrated TNM stage, or individual T, N and M components for each of these three categories. A value of 'X' for any of the T, N and M components is not accepted as valid.

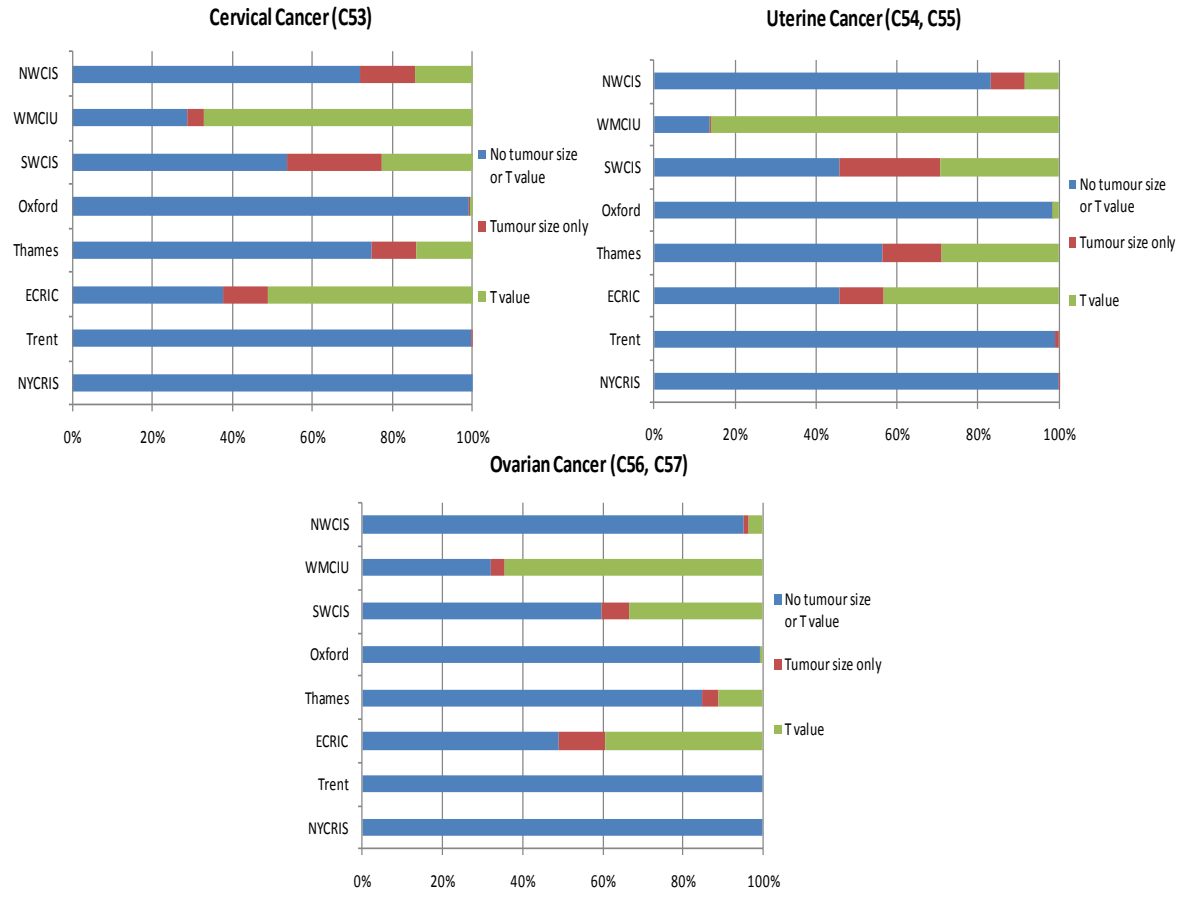
The chart below shows the proportion of cases with any combined TNM information for each of the three sites, for those diagnosed in 2006-2008. Both WMCIU and ECRIC have a high proportion of cases with a TNM stage for all three sites; similar to the proportion of cases with a FIGO stage.



Tumour Extent

Tumour extent may be captured in several fields submitted to the NCDR. These are the three individual T components from clinical, pathological or integrated, and the tumour size field, which records the size of the tumour in millimetres. The tumour size ranges from 1mm to 989mm. The number of tumours with an extremely large (and most likely incorrect) measurement recorded is negligible; there were only 15 tumours recorded as measuring >400mm. There are 106 cases with a tumour size of 0, almost half of which are FIGO stage 1A1. These were not included as a valid tumour size.

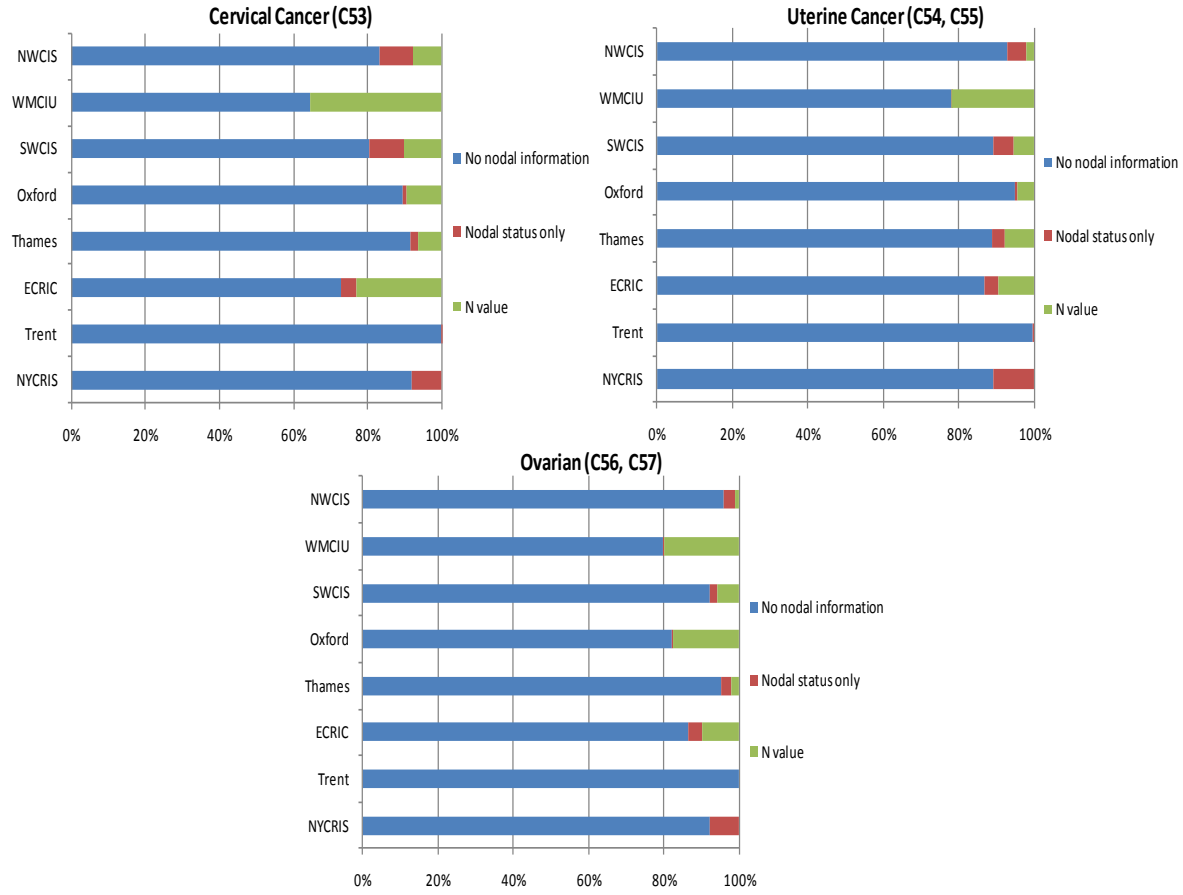
The following charts show the proportion of cases in 2006-2008 where there is: no tumour extent information in any field identified above; a tumour size was recorded but there was no valid T component recorded; or a valid T component was recorded. WMCIU have the greatest proportion of cases with tumour extent information available and Trent, NYCRIS, OCIU have the smallest proportion of cases. As the T component may be derived directly from the tumour size it shows that, for some registries, the T component could have higher levels of completion. For example, for both cervical and uterine cancer, SWCIS have around 20% of cases where there is a tumour size but no individual T component.



Nodal Status

Nodal status may be captured in the component N fields or in the 'nodes positive' field, which records the number of nodes that are found to be positive for cancer cells. There is also an additional field which records the number of nodes examined. A valid nodal status cannot be assigned for records that have a value of 0 for both 'nodes examined' and 'nodes positive'.

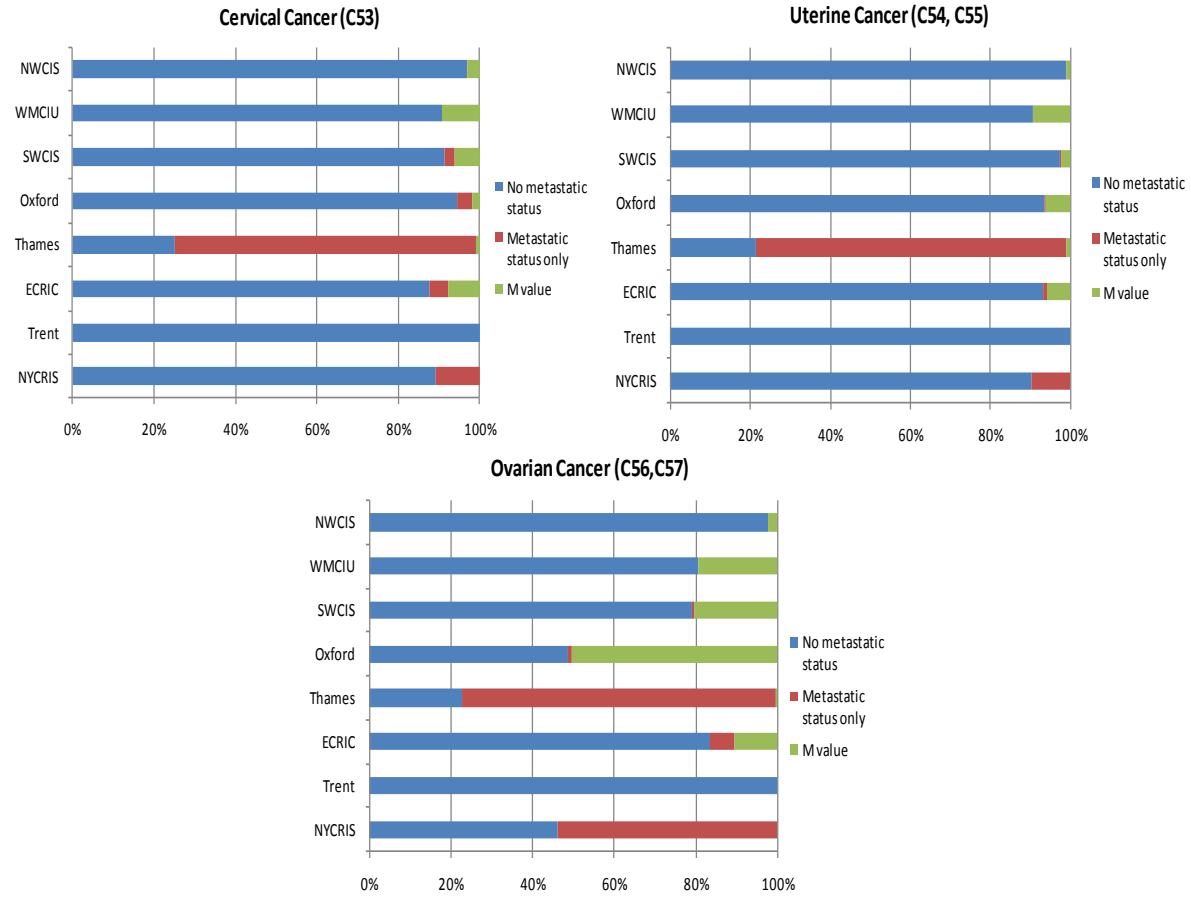
The following charts show the proportion of cases in 2006-2008 where there is: no nodal information in any field identified above; the number of nodes positive was recorded but there was no valid N component recorded; or there was a valid N component available. As the N component can be derived from information about the number of nodes positive it shows that for some registries, the N component could have higher levels of completion. There are much lower proportions of cases with nodal information than tumour extent information; all registries having less than 40% of cases with any nodal information. WMCIU has the highest proportions of cases with nodal information available, having 20-30% of cases with a valid N component. NYCRIS has no component N value; however around 5-10% of cases do have information regarding the number of nodes found to be positive. Trent has no nodal information recorded in any of the fields available in the NCDR.



Metastatic Status

Information about whether a cancer has metastasised to other parts of the body can be recorded in various fields in the NCDR; the M component fields or in the 'metastases' field which indicates either yes or no. Any cases where the metastatic value is 'X' are classed as having an unknown metastatic status.

The following charts show the proportion of cases in 2006-2008 where there is: no metastatic information in any field identified above; there was a valid indication in the 'metastases' field but there was no valid M component recorded; or there was a valid M component recorded. As the M component can be derived from information about the metastatic disease it shows that for some registries, the M component could have higher levels of completion. Thames has almost 80% of cases for all three cancers with a valid indication in the 'metastases' field; however there are very few cases with a valid M component. NYCRIS is similar, particularly for ovarian cancer. Trent has no metastatic status information available in the NCDR.



Treatment

The 2008 iteration of the NCDR has four flags which indicate whether a person has received hormone therapy, chemotherapy, radiotherapy or surgery. The first of these flags is not examined here as there are very few cases where hormone therapy has been indicated; 3% of all gynae cases in the NCDR are recorded as having received this type of treatment. There are two ways in which registries have completed the treatment fields. If there is no evidence of a patient receiving a form of treatment then ECRIC has left the flag blank rather than assuming that the lack of information implies that no treatment was received. Trent has also left the treatment flag blank for the majority of records, although a small proportion of cases are flagged as 'No'. The other registries indicate either 'Yes' or 'No'.

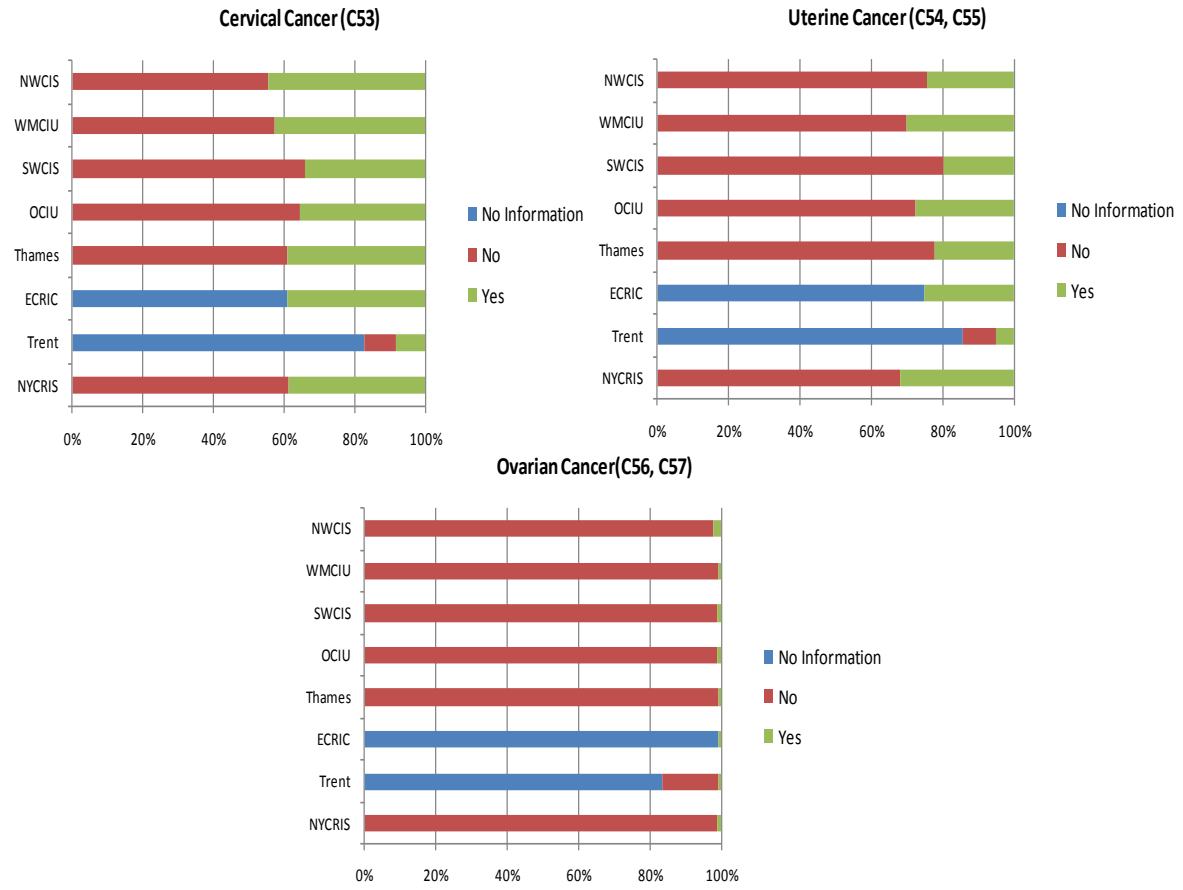
For all treatment flags, there should only be a 'Yes' flag if the treatment was received within 6 months of the diagnosis date. However, caution must be taken when using the flag as it may underestimate the true treatment rates. For example, it is known that Trent decided not to actively collect radiotherapy treatment data locally as this information was to be provided centrally, via the Radiotherapy Episode Statistics (RES). Radiotherapy treatment rates for Trent derived from the NCDR flag will therefore be underestimates of the true rate. Between registries there may be other inconsistencies in the recording of treatment in the NCDR because of the differences in: the source of information; whether all treatment information or only treatment with a curative intent was recorded; or the set of OPCS 4[2] codes used to define relevant treatment may have differed between registries.

The dates of treatment are not available in the NCDR; it is possible to supplement this information by linking to the HES data or treatment table submitted by the registries.

[2] OPCS 4 codes are Office of Population, Censuses and Surveys Classification of Surgical Operations and Procedures (4th revision)

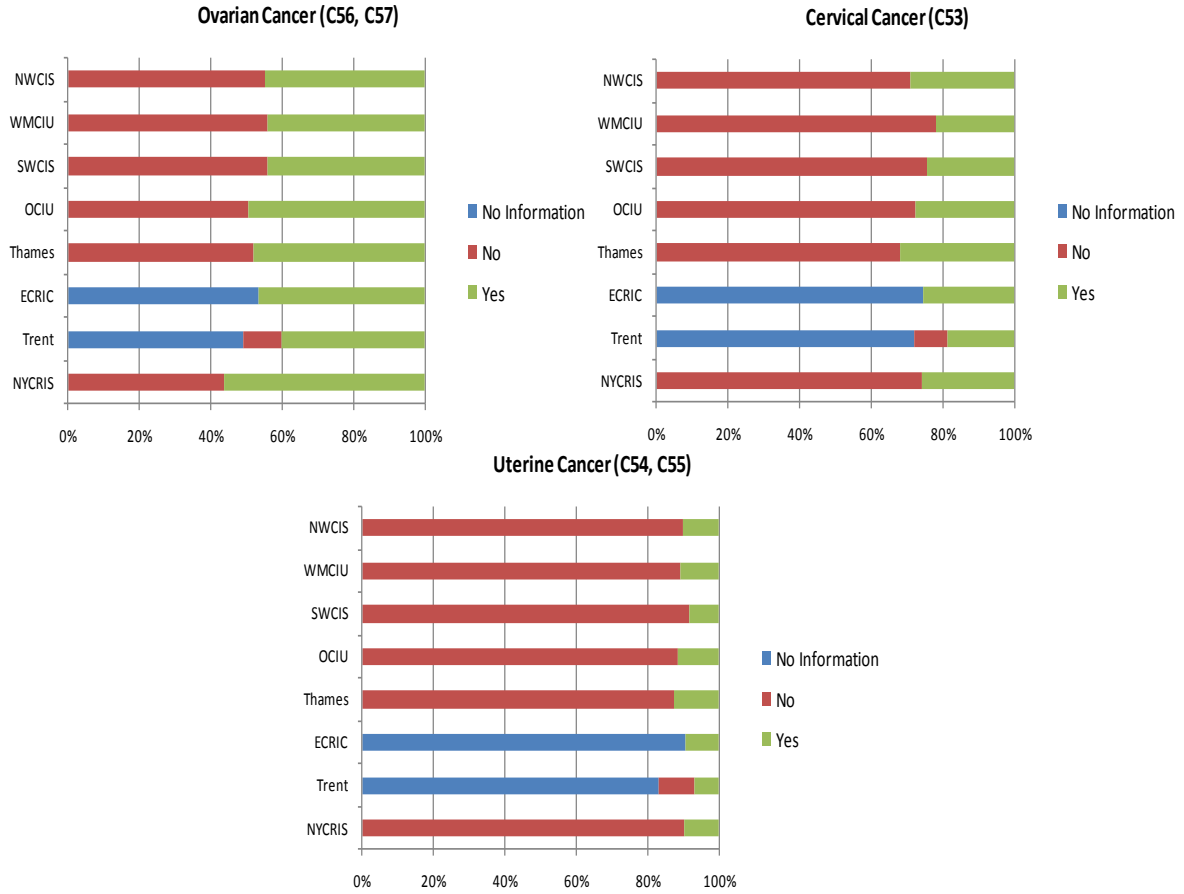
Radiotherapy

The proportion of cases in 2006-2008 indicated as receiving radiotherapy varies by registry for each cancer. In total around 40% of patients are identified as having received radiotherapy for cervical cancer; the figure is less than 10% for Trent. The proportion of uterine cancer patients receiving radiotherapy is around 20-30% across registries, although for Trent this is around 5%. The proportion of ovarian cancer patients receiving radiotherapy is around 1-2% as this kind of treatment is rarely administered for this disease. The variation between registries in the proportion of patients receiving radiotherapy is most likely due to variation in the availability of data rather than differences in the way patients are treated (see the introduction in the treatment section)



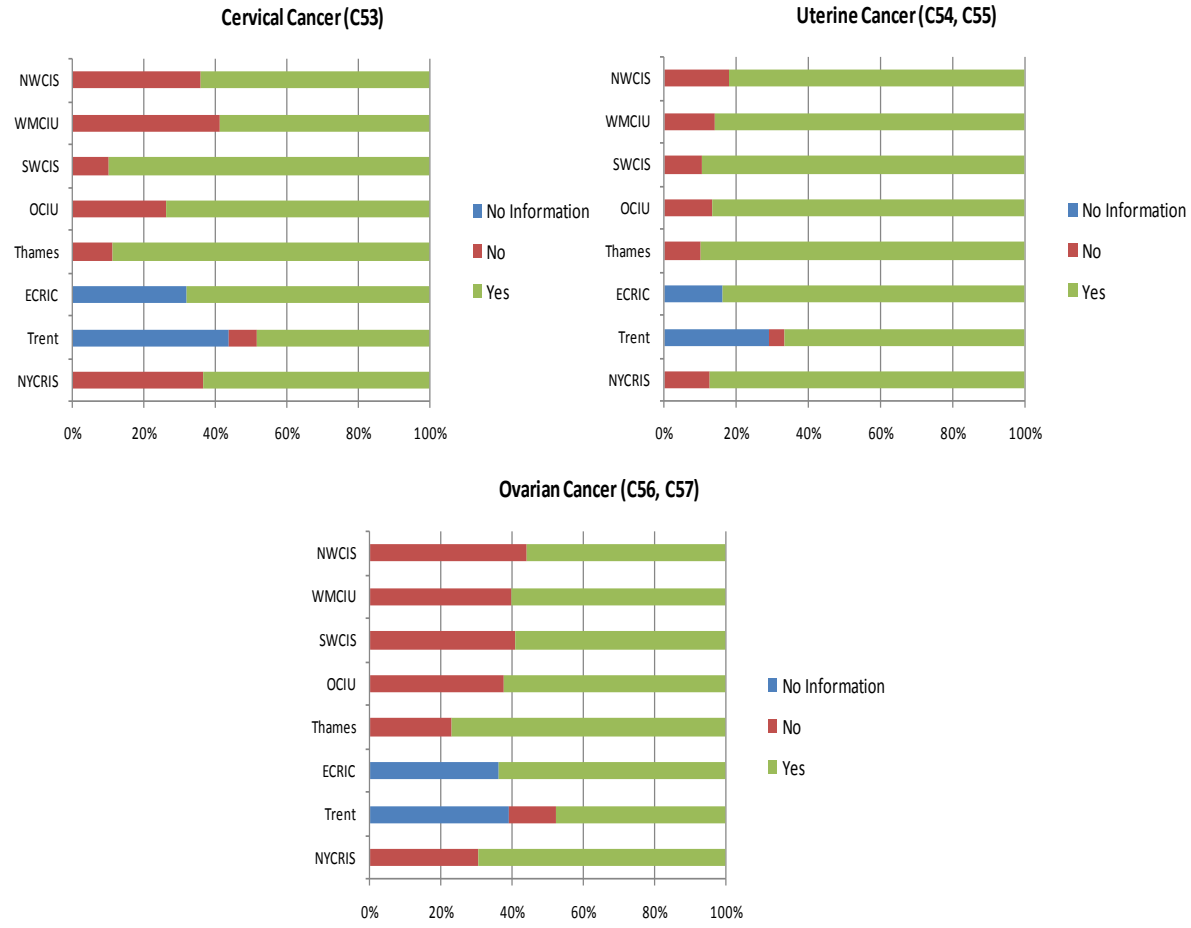
Chemotherapy

The proportion of cases indicated as receiving chemotherapy varies between registries. For cervical cancer, around 20-30% of patients have received chemotherapy, for uterine cancer patients around 10%, and for ovarian cancer patients around 40-55%. Trent has the lowest proportion of cases indicating that the patient received chemotherapy treatment. This variation may reflect differences in the availability and source of chemotherapy data rather than differences in the way patients are treated.



Surgery

The proportion of patients identified as receiving surgery for gynaecological cancers varies widely across registries. For cervical cancer, around 90% of patients were identified as having received surgery in SWCIS, whilst in Trent only around 50% of patients appear to have received surgery. For uterine cancer, Trent identified almost 70% of patients as having received surgery, whilst all other registries identified over 80%. There is a similar result for ovarian cancer. Rather than indicating differences in how patients are treated, the variation between registries is most likely due to differences in sources of information or the way in which relevant surgery has been defined (please see the introduction in the treatment section).



Appendix

Registry Abbreviations and Names

NYCRIS	Northern and Yorkshire Cancer Registry Information Services
Trent	Trent Cancer Registry
ECRIC	Eastern Cancer Registry and Information Centre
Thames	Thames Cancer Registry
OCIU	Oxford Cancer Intelligence Unit
SWCIS	South West Cancer Intelligence Service
WMCIU	West Midlands Cancer Intelligence Unit
NWCIS	North West Cancer Intelligence Service

Charlson Score groups and scores for co-morbidity conditions

Charlson Group	Description	Charlson Score	Notes
1	Acute Myocardial Infarction	1	
2	Congestive Heart Failure	1	
3	Peripheral Vascular Disease	1	
4	Cerebral Vascular Accident	1	
5	Dementia	1	
6	Pulmonary Disease	1	
7	Connective Tissue Disorder	1	
8	Peptic Ulcer	1	
9	Diabetes	1	
10	Diabetes Complications	2	Only highest score is counted
11	Paraplegia	2	
12	Renal Disease	2	
13	Cancer	2	
14	Metastatic Cancer	N/A	Derived from cancer registry data rather than HES data.
17	Liver Disease	1	
15	Severe Liver Disease	3	Only highest score is counted
16	HIV	6	

FIND OUT MORE:

Trent Cancer Registry
Trent Cancer Registry is the lead Cancer Registry for gynaecological cancers

http://www.empho.org.uk/tcr/data.aspx

Other useful resources within the NCIN partnership:

Cancer Research UK CancerStats – Key facts and detailed statistics for health professionals

http://info.cancerresearchuk.org/cancerstats/

The NCIN is a UK-wide initiative, working closely with cancer services in England, Scotland, Wales and Northern Ireland, and the National Cancer Research Institute (NCRI), to drive improvements in standards of cancer care and clinical outcomes by improving and using the information it collects for analysis, publication and research. In England, the NCIN is part of the National Cancer Programme.