Public Health England

National Cancer Intelligence Network

Gynaecological Sarcoma Surgical Treatment

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The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

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Executive summary

Gynaecological sarcomas are an exceptionally rare form of cancer which collectively account for 3-4% of all gynaecological cancers. Approximately 280 gynaecological sarcomas are diagnosed annually, with an age-standardised incidence rate of 11 per million female population. Uterine sarcomas account for approximately 83% of gynaecological sarcomas, and leiomyosarcoma is the most common histological sub-type, accounting for 52% of diagnoses.

Gynaecological sarcomas, particularly uterine leiomyosarcomas, are associated with significantly poorer outcomes than gynaecological carcinomas. This report fills a void in publicly available data reporting the NHS hospital Trusts where gynaecological sarcoma patients are treated surgically.

Between 2001 and 2010, there were 2,867 new diagnoses of gynaecological sarcoma in England. The proportion of surgery related hospital admissions undertaken within NHS hospital Trusts hosting a gynaecological cancer MDT increased significantly from 46% to 65% between 2001-2005 and 2006-2010, most probably as a result of the Improving Outcomes Guidance for Patients with Gynaecological Cancer, which was published in 1999. However, in 2001-2010, 182 different NHS hospital Trusts surgically treated at least one gynaecological sarcoma patient, and 59 NHS hospital Trusts had a surgical caseload of fewer than five patients.

Most of the surgery related hospital admissions (88%) occurred following a planned hospital admission. The majority of surgery related hospital admissions (89%) were overseen by consultants with a specialty in gynaecology recorded in HES. A small proportion of surgery related hospital admissions (7%) were overseen by consultants with a specialty in obstetrics. The corresponding GMC specialty codes confirmed that these consultants specialised in “obstetrics and gynaecology” or “gynaecological oncology”.

It is currently not possible to identify whether gynaecological sarcoma patients were discussed in a gynaecological cancer MDT or a sarcoma MDT. This information will be collected within the Cancer Outcomes and Services and Dataset from April 2016.

The analyses in this report show the complexity of the surgical management of patients with gynaecological sarcoma. Uterine sarcomas are usually diagnosed following a hysterectomy for suspected fibroids, so a sarcoma diagnosis would not have been obvious at the time of presentation. Further analyses are required to establish other interventions that may have taken place prior to surgical treatment in order to understand why patients with uterine leiomyosarcoma have such poor outcomes.

Acknowledgements

This is a joint publication between the Public Health England (PHE) West Midlands Knowledge and Intelligence Team (WM KIT), the National Cancer Intelligence Network (NCIN) analytical lead for sarcoma, and the East Midlands KIT, the NCIN analytical lead for gynaecological sarcomas.

The authors would like to thank the London School of Hygiene and Tropical Medicine for the life tables used in these analyses.

Introduction

Sarcomas are a group of rare heterogeneous neoplasms which can arise in the bones or within the soft and connective tissue of the body. Bone sarcomas account for approximately 0.2% of malignant tumours diagnosed annually[1]; soft tissue sarcomas are slightly more common and represent approximately 1%[2]. Over 80 different types of sarcoma were diagnosed in England between 1990 and 2000. The most common types of soft tissue sarcoma are leiomyosarcoma, liposarcoma and sarcoma NOS[2]. The most common cancer sites for soft tissue sarcomas to arise are within the extremities (23%) and within the connective tissues of the trunk (13%).

Approximately 13% of soft tissue sarcomas arise in the gynaecological organs[3] and 3-4% of all gynaecological cancers are soft tissue sarcomas[4]. Due to the diverse morphological sub-types and their rarity, treatment of gynaecological sarcomas is challenging. Because of the difficulty in accurately identifying gynaecological sarcomas, the survival rate of even apparently early stage tumours is low. Leiomyosarcomas, in particular, are very aggressive tumours and are associated with poor prognosis even when confined to the uterus[5]. The 5-year relative survival of uterine sarcoma has been estimated at around 30%[6], compared to 77% for women with any type of uterine carcinoma (Cancer Stats UK[7]).

The Improving Outcomes Guidance (IOG) guidelines for cancer advise commissioners on how to improve the care of patients with particular cancers. These guidelines are published by the National Institute for Health and Care Excellence (NICE). The Improving Outcomes Guidance (IOG) for Gynaecological Cancers, which was published in 1999, specifies that women with higher risk tumours (including sarcomas) should be treated by specialist gynaecological oncology teams at cancer centres. The Gynaecological Cancer IOG does not refer to gynaecological cancer or sarcoma multi-disciplinary teams (MDTs) or specialists[8] as the MDT model for cancer patients was not endorsed until 2000 when then National Health Service National Cancer Plan was published. The Improving Outcomes Guidance (IOG) for Bone and Soft Tissue Sarcoma, which was published in 2006, advised that any patient with a diagnosis of bone or soft tissue sarcoma should have their care overseen by a sarcoma MDT[9], and that, for patients with site specific sarcomas such as gynaecological or head and neck tumours, there should be an established relationship between the sarcoma and site specific MDTs.

Publically available information on gynaecological sarcoma incidence, outcomes and treatment (surgery, chemotherapy or radiotherapy) is currently very limited, and is generally based on small cohorts of patients recorded in hospital treatment databases. The aim of this report is to establish where patients with gynaecological sarcomas were surgically treated in the period 2001-2010, and whether the NHS hospital Trust of surgery hosted a sarcoma MDT or a specialist gynaecological cancer MDT. The report also investigates patterns of care to see if referrals to an appropriate specialist centre increased following the publication of the Gynaecological Cancer and/or Sarcoma IOGs.

Methods

The West Midlands Knowledge and Intelligence Team (WMKIT) is the National Cancer Intelligence Network (NCIN) national lead analytical team for bone and soft tissue sarcoma. The East Midlands Knowledge and Intelligence Team (EMKIT) is the NCIN national lead for gynaecological cancer. The lead KITs analyse national data on the incidence, mortality, survival and treatment of their respective specific cancer site(s) in England. These analyses are often conducted using the National Cancer Data Repository (NCDR), an evolving source of data compiled by the NCIN and containing details of all tumours and patients registered in England. The current version of the NCDR includes all malignancies diagnosed in England between 1990 and 2010.

Soft tissue sarcomas are classified by both the 10th revision of the International Classification of Diseases (ICD-10) site code and an ICD-O3 morphology code. Within the ICD-10 coding system, the prefix ‘C’ locates the code within the ‘neoplasm’, or cancer, subgroup, and the following numbers localise the tumour to a specific area of the body. A two number string denotes a general area of the body, while a three number string represents a more specific area; for example, ‘C-54’ denotes a malignant neoplasm of the corpus uteri (uterus), and ‘C-541’ represents a malignant neoplasm of the endometrium. Tumours arising within the gynaecological tract were identified using the ICD-10 codes listed in Appendix A.

The Hospital Episode Statistics (HES) dataset to which the KITs have access, contains all inpatient and day case patients who have at least one admission where any tumour (benign or malignant) is recorded. The HES data utilised for the purpose of these analyses include all hospital admissions between 1997 and March 2012. The HES dataset records information such as the hospital of treatment or care, the type of surgical treatment provided, and other diagnoses observed in the patient. Primary surgical treatment for gynaecological cancer was identified within the HES data as any major surgical resection undertaken within six months of initial diagnosis (Appendix B). Consultant specialist codes recorded in HES were used to establish the speciality of the consultant overseeing the patient’s care during each hospital admission.

Minimal access laparoscopic surgery for endometrial cancer is a surgical procedure performed by making small incisions in the abdomen. Specialist surgical instruments are then inserted into the incisions allowing the uterus to be removed through the vagina. This is an alternative to open access surgery which is performed through an incision in the abdomen or vagina. The methodology identified by the EMKIT was adopted for identifying laparoscopic surgery recorded in HES[10].

The list of gynaecological cancer specialist NHS hospital Trusts was provided by the EMKIT. The Trusts with gynaecological cancer specialist status have changed over the

years. Therefore, the 2010-2011 Trust list was utilised as a basis to define patients who were treated within a NHS hospital Trust which hosts a gynaecological oncology specialist MDT. However, although a Trust may host a particular type of specialist MDT, currently, it is not possible to identify which MDTs within a hospital Trust discussed each patient. This information will be collected within the Cancer Outcomes and Services Dataset (COSD) from April 2016 onwards.

Age-standardised (ASR) and age specific (ASIR) incidence rates are expressed as numbers per million population throughout. Confidence intervals around incidence rates were calculated using the gamma method. Relative survival is defined as the observed survival in the patient group divided by the expected survival of the general population, matched by age, sex, and calendar year. Relative survival was calculated in Stata (v.11) using the strs programme which calculates relative survival estimates using the Ederer II method. Five-year relative survival was calculated using 5-year rolling averages. National life tables were obtained from the Cancer Research UK Cancer Survival Group at the London School of Hygiene and Tropical Medicine.

The Index of Multiple Deprivation 2010 (ID2010) combines a number of indicators, covering a range of economic, social and housing issues, into a single deprivation score for each small area in England. This allows each area to be ranked according to its level of deprivation. ID2010 scores are produced at Lower Super Output Area (LSOA) level, of which there are 32,482 in England[11]. The income domain score was used as the deprivation indicator for England in this report. ID2010 scores can be grouped into five ranges (quintiles), each containing one fifth of the English population. To obtain an indication of the deprivation status of each patient, postcode of residence was linked to the ID2010 score for the small area in which the patient lived at the time of diagnosis. Patients were then allocated to a deprivation quintile based on their ID2010 score.

Gynaecological sarcoma diagnosis and staging

Patients with gynaecological sarcoma tend to present with nonspecific symptoms such as vaginal bleeding, or a gradually increasing mass causing pain[12]. The suspected diagnosis for premenopausal women who present with menstrual symptoms and an enlarged uterus is benign fibroids (leiomyoma). The majority of uterine sarcomas are thus diagnosed on the histopathological evaluation of a hysterectomy or myomectomy specimen[13]. Uterine sarcomas may also be diagnosed preoperatively by imaging[14].

The majority of soft tissue sarcomas are staged according the TNM staging system, which requires information regarding the tumour size, nodal involvement, the presence of metastases and the grade of tumour. However, due to their anatomical location within the body, gynaecological sarcomas are staged according to the International Federation of Gynaecology and Obstetrics (FIGO) staging system[15]. In the FIGO staging system published in 1988, uterine sarcomas were staged as endometrial cancers which did not reflect their clinical behaviour. The latest version of the FIGO staging system (published in 2009) includes a separate entity for uterine sarcoma which is based on the criteria used for other soft tissue sarcoma sites. This is described as a “best guess” staging system, so data will be collected and evaluated for further developments of uterine sarcoma FIGO staging. It should be noted that the FIGO staging system requires lymph node dissection, a practice which remains controversial for uterine leiomyosarcoma as metastatic rates to lymph nodes are low and are usually associated with intra-abdominal disease[16]. Regardless of the underlying staging system used for soft tissue sarcomas, the completeness of the components required to calculate a stage for gynaecological sarcomas is less than 2% in England. This information should now be being routinely collected and recorded by specialist MDTs as part of the COSD.

In the FIGO staging system, Stage IIIC indicates metastases to pelvic and or para-aortic lymph nodes and Stage IVB indicates distant metastases. HES data record all patient conditions diagnosed during an inpatient or day case NHS hospital admission. If a cancer patient has metastases listed as a condition during a hospital admission, this should be reflected in the HES data. If a metastases related admission occurs within 4 months of a cancer diagnosis, this can be considered a crude indicator of metastases at diagnosis. This is not a perfect method of identifying patients with FIGO Stage IIIC/IVB cancers as the method relies heavily on patients being admitted to hospital and for metastatic cancer sites to be accurately diagnosed and recorded during a hospital admission. However, investigations within the WMKIT have found significant differences in 5-year survival between patients with and without recorded metastases in the expected direction (results not presented).

Incidence

Between 2001 and 2010, 2,867 patients were diagnosed with a gynaecological sarcoma in England. Female age standardised incidence rates fluctuated around 11 per million female population (Figure 1 [see Appendix C for supporting data]). Around 280 gynaecological sarcomas were diagnosed annually. Age specific incidence rates rose sharply from the age of 40 years, and were highest in females in the 55-59 and 60-64 age groups (14 and 13 per million female population respectively). Rhabdomyosarcoma was the predominant diagnosis in the small number of gynaecological sarcomas diagnosed in infants (Figure 2 [see Appendix C for supporting data]).

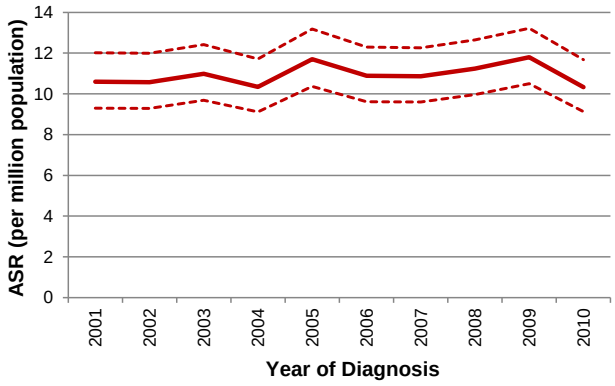

Figure 1: Gynaecological sarcoma age standardised incidence rates (England 2001-2010)

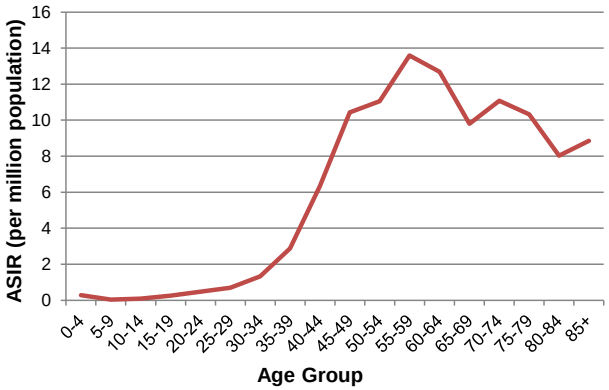

Figure 2: Gynaecological sarcoma age specific incidence rates (England 2001-2010)

The most common specific anatomical location for gynaecological sarcomas to arise was the uterus, which accounted for 83.6% of all diagnoses. The most common histological diagnosis was leiomyosarcoma which accounted for 47.5% of diagnoses.

Survival

Gynaecological sarcoma 5-year relative survival rates have increased significantly over the last 25 years, but still remain below 50%. For patients diagnosed between 1985 and 1989, the 1-year and 5-year relative survival rates were 59% and 34% respectively. For those diagnosed between 2000 and 2004, relative survival rates increased significantly to 69% at one year and 48% at 5 years. The most common histological gynaecological sarcoma sub-type, uterine leiomyosarcoma, had a particularly poor 5-year relative survival of 37% which is significantly lower than the survival rate of 48% seen in Norway (1983-1987)[17]. The uterine endometrial stromal sarcoma (ESS) 5-year relative survival rate was significantly higher at 68%, consistent with the 63% demonstrated in a study from Austria[18]. However there was significant variation

across the individual gynaecological anatomical sites, with patients with vulvo-vaginal sarcomas having the highest 5-year relative survival (63%) and patients with sarcomas in very rare gynaecological sites (for example, the fallopian tube) having the lowest 5-year relative survival (30%).

Surgical treatment

Variation in Surgical Treatment with Age, Diagnosis Year and Stage at Diagnosis

Although inpatient/day case HES has been collected since 1997, to ensure that the most complete data were available, for the purposes of this report the diagnosis years were limited to the period 2001 to 2010, during which time 2,867 gynaecological sarcomas were diagnosed. The coding of laparoscopic surgery for patients with uterine sarcoma was inconsistent throughout the NHS hospital Trusts in England. Of the 2,398 patients diagnosed with a uterine sarcoma in England between 2001 and 2010, 1,600 were treated surgically and 89 (5.8%) had laparoscopic surgery recorded. Of the 234 patients diagnosed with a uterine sarcoma in 2010, 164 were treated surgically and 22 (13%) had a laparoscopic surgery recorded. This is well below the 27.6% reported by the EMKIT for all patients with uterine cancer diagnosed in 2010. It is possible that the majority of uterine sarcomas present as large masses (fibroids) which may be considered unsuitable for laparoscopic surgery by gynaecologists. The quality of the information with regards to laparoscopic surgery requires further investigation before this can be routinely reported on for gynaecological surgery. For the purpose of the treatment analyses in this report all major resections are included (see Appendix B) without specification of the method of resection ie open surgery or laparoscopic.

Of the 2,867 patients diagnosed with gynaecological sarcoma in 2001-2010, a HES record relating to an admission for a major resection was identified for 1,887 (66%). A small number of patients (62, 3.3%) were treated in more than one NHS hospital Trust during the six month period following their diagnosis. Patients aged 80 years and over were less likely to be treated surgically, with only 118 out of 246 (48%) having surgical treatment (Figure 3, [see Appendix C for supporting data]). Of the 128 patients in this age group who were not treated surgically, the histological diagnoses were predominantly sarcoma NOS and leiomyosarcoma. Factors such as co-morbidity and stage at diagnosis require investigation to establish why these older patients were not treated surgically and whether or not they received radiotherapy and/or chemotherapy.

The numbers and proportion of patients receiving major resection for gynaecological sarcoma increased from 63.3% (878/1,388 patients) in 2001-2005 to 68.2% (1,009/1,479 patients) in 2006-2010. This difference is statistically significant (p=0.0051). HES records were investigated to identify the proportion of gynaecological patients who had metastases recorded during a hospital admission within four months of their diagnosis. Of the 2,867 patients diagnosed with a

gynaecological sarcoma, 504 (18%) had a record of metastasis at diagnosis, and 259 (51%) of these had a surgery related hospital admission.

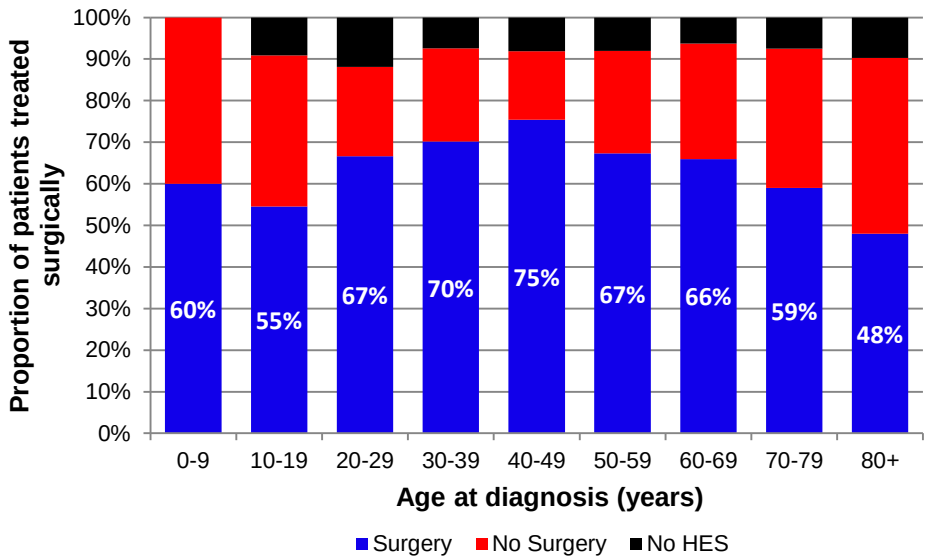

Figure 3: Variation with age in the proportion of gynaecological sarcoma patients treated with a major resection (England: 2001-2010)

Specialist MDTs Hosted by Trusts Providing Surgical Treatment

With the information currently available, it is not possible to identify whether patients with gynaecological sarcomas were discussed by a gynaecological cancer and/or sarcoma MDT. However, it is possible to identify the nature of the MDTs hosted by the NHS hospital Trusts where patients received their surgical treatment. Figure 4 shows how the number of gynaecological sarcomas treated within each NHS hospital Trust in England in 2001-2005 and 2006-2010 varied with the nature of the specialist MDT hosted by that Trust. Figure 5 summarises these data for the main types of specialist MDT.

During the 10-year period studied, 182 different NHS hospital Trusts were identified as having treated at least one gynaecological sarcoma. However, 48% (980/2,029) of major resections were performed within the 31 Trusts treating 20 or more gynaecological sarcomas in total. The Trust with the largest caseload (which hosts a gynaecological cancer MDT only) oversaw major resections for 67 tumours over the 10-year period (around six tumours annually). In 2001-2010, of the 2,029 hospital admissions relating to surgical treatment for a gynaecological sarcoma, 1,146 (56.5%) were within Trusts hosting a gynaecological cancer MDT; 820 (40%) within Trusts hosting a gynaecological cancer MDT only, and a further 326 (16%) in Trusts hosting both gynaecological cancer and sarcoma MDTs (Figure 5 [see Appendix C for supporting data]).

In 2001-2010, of the major resections recorded in HES, 40.1% (814 in total) were performed in a local NHS hospital Trust which did not host a specialist gynaecological cancer or sarcoma

MDT. In 2001-2005, 165 different NHS hospital Trusts treated at least one gynaecological sarcoma, and only 349 (37%) of major resection related admissions were undertaken within the 31 Trusts treating 20 or more gynaecological sarcomas in the 10-year period studied. In 2006-2010, 144 different Trusts treated gynaecological sarcoma and 631 (56.8%) of major resection related admissions were undertaken with the 31 Trusts treating 20 or more gynaecological sarcomas in total. These differences which are indicative of increasing specialisation with time are statistically significant ($p<0.0001$). However, in the most recent data for patients diagnosed with a gynaecological sarcoma in 2010, there were still 83 different NHS hospital Trusts providing surgical treatment for at least one patient with a gynaecological sarcoma.

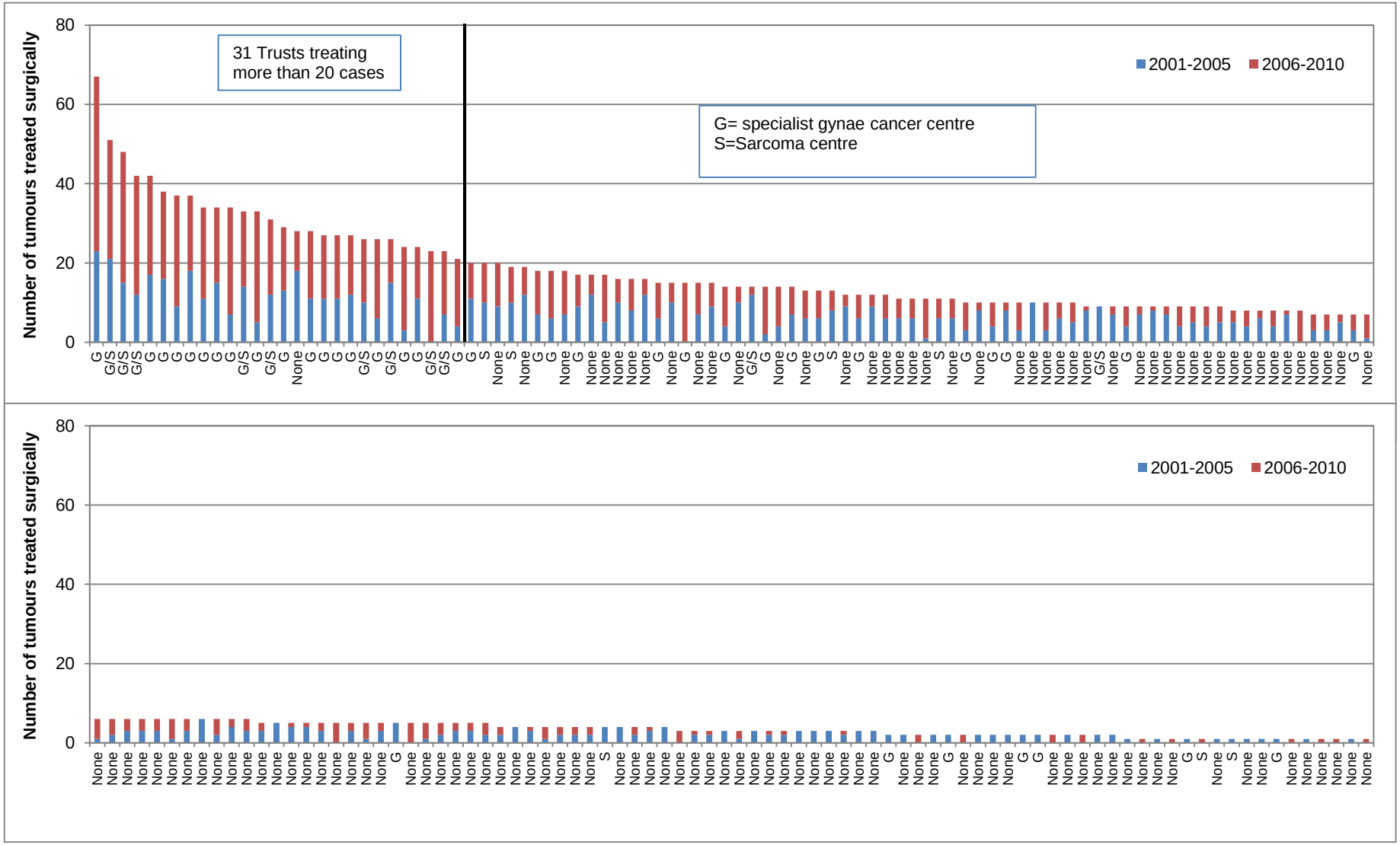

Figure 4: Number of gynaecological sarcomas treated within each NHS hospital Trust (England 2000-2010)

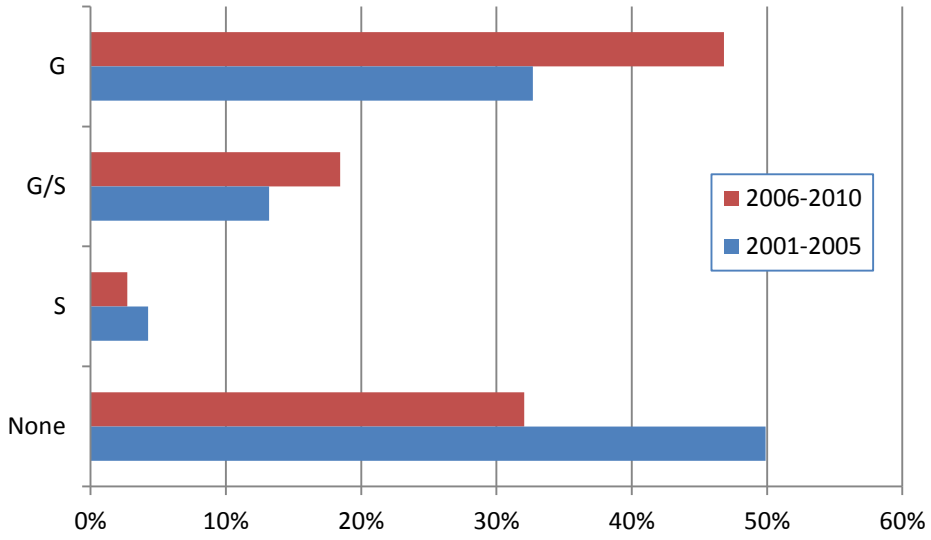

Figure 5: Number of gynaecological sarcomas treated within hospital trusts with MDT services available (England 2001-2010)

The proportion of gynaecological sarcomas treated in NHS hospital Trusts with a gynaecological cancer MDT, or a sarcoma and a gynaecological cancer MDT, increased from 46% in 2001-2005 to 65% in 2006-2010 ($p<0.0001$). There are nine NHS hospital Trusts in England which host both a sarcoma MDT and a specialist gynaecological cancer MDT. Collectively, 326 (16%) of the surgery-related hospital admissions were undertaken in these Trusts. The proportion of surgery-related to admissions to these Trusts increased statistically significantly from 13% to 18% ($p=0.0013$) between 2001-2005 and 2006-2010.

There were corresponding decreases in the proportion of patients treated surgically in local NHS hospital Trusts which did not host a specialist gynaecological cancer or sarcoma MDT from 49.9% to 32.0% ($p<0.00001$). These significant changes are presumably as a result of the reorganisation of gynaecological cancer services which followed the publication of the Gynaecological Cancer IOG[8]. The relevance of the referrals to a sarcoma centre is not known for certain as the majority of these are co-located with gynaecological cancer specialist hospitals.

Consultant Specialities Providing Surgical Treatment and Surgical Procedure Type

HES data record the specialty of the consultant overseeing the care of patients during any particular hospital admission episode; this does not necessarily reflect the specialty of the consultant undertaking the surgery. The care of patients with gynaecological sarcomas was predominantly overseen by consultants specialising in gynaecology (89%). A small proportion of patient care was overseen by consultants specialising in obstetrics (7%) and general surgery (1%). (Figure 6 [see Appendix C for supporting data]).

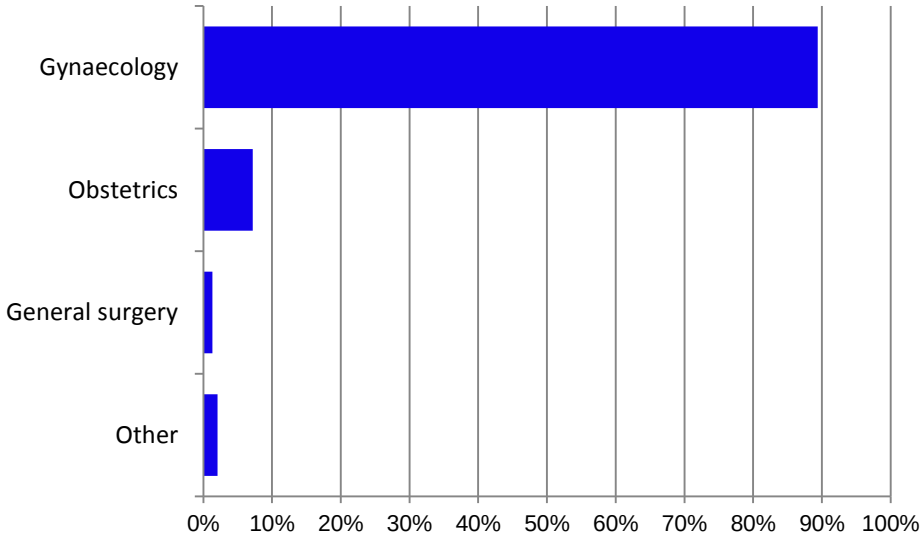

Figure 6: Number of gynaecological sarcoma admissions overseen by each consultant specialty (England: 2001-2010)

Consultants recorded as specialists in obstetrics within the HES data were compared with the consultant specialty recorded in the General Medical Council (GMC) database. All consultants who specialised in gynaecology or obstetrics were recorded as “obstetrics and gynaecology” or “gynaecological oncology” in the GMC database.

A comprehensive list of the most common surgical OPCS4 procedure codes recorded for patients with gynaecological sarcoma is provided in Appendix B. There were 48 different surgical procedures undertaken during 2,029 surgery-related hospital admissions. The most commonly performed surgical procedures were “total abdominal hysterectomy” and “bilateral salpingoophorectomy” (74%, [1,497/2,029]) and (71% [1,435/2,029] of surgery-related hospital admissions respectively). These were by far the most commonly performed surgical procedures over the 10-year period, with the next most frequent procedure being recorded in only 5% (106/2,029) of surgery-related hospital admissions.

Characteristics Of Tumours Not Treated Surgically

The stage of the tumour at diagnosis is the most important prognostic factor for patients with cancer and generally determines their course of treatment. Sarcoma staging data is currently incomplete, although this information should now be being collected by specialist gynaecological cancer and sarcoma MDTs in the COSD. In the absence of staging data,

logistic regression was applied to investigate the patient and tumour characteristics of sarcomas which were not treated surgically. The factors investigated were age at diagnosis, deprivation status, ethnicity, anatomical cancer site, morphological sub-type and the presence of metastases at diagnosis.

Figure 7 [see Appendix C for supporting data] shows how the factors investigated affected the likelihood of gynaecological sarcomas having surgical treatment. A high Odds Ratio (above 1 and highlighted in black) indicates that a factor significantly decreased the likelihood of gynaecological sarcomas having surgical treatment. A low Odds Ratio (below 1 and highlighted in black) indicates that a factor significantly increased the likelihood of gynaecological sarcomas having surgical treatment. An odds ratio of 1.025 indicates that for every 1-year increase in age, the odds of surgery were 2.5% lower.

The factors appearing to decrease the likelihood of a sarcoma having surgical treatment were: the presence of metastases at diagnosis (OR=3.0, p<0.0001), tumours arising specifically in the vulvo-vaginal region (when compared with uterine sarcomas, OR=2.8, p<0.0001), a diagnosis of sarcoma NOS (OR=2.1, p<0.0001) and increasing age (OR=1.0, p<0.0001). A diagnosis of adenosarcoma increased the likelihood of having surgery (OR=0.4, p<0.0001) as did a patient being in the most deprived quintile (Quintile 5, [OR=0.6, p=0.0001]) or in the second most affluent deprivation quintile (Quintile 2, OR=0.8, [p=0.05]). The patient's ethnicity was not a significant factor affecting surgery (Asian: OR=1.7, p=0.06, Black: OR=1.6, p=0.06).

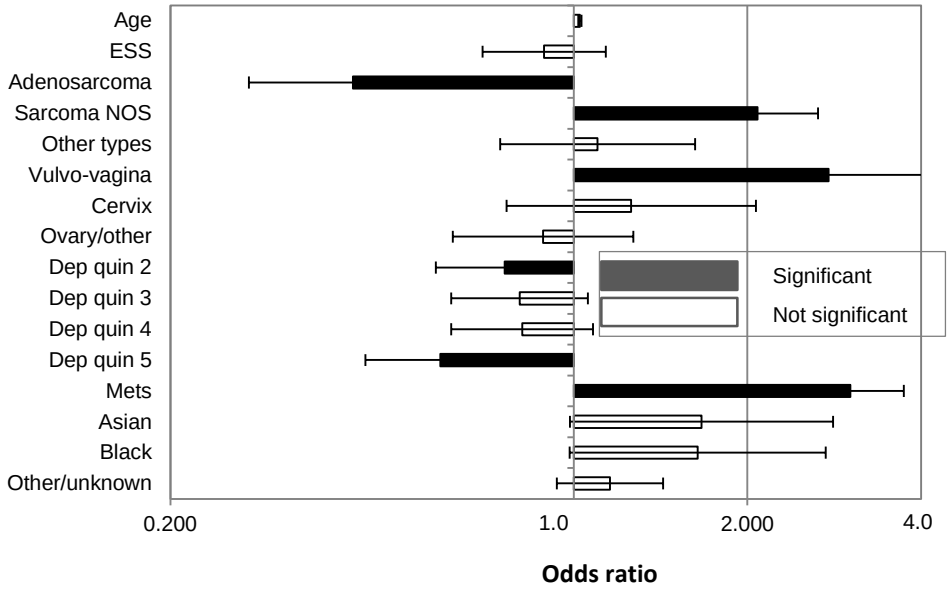

Figure 7: Factors affecting the likelihood of gynaecological sarcomas not receiving surgical treatment (England: 2001-2010)

Increasing age may be correlated with more comorbidity, so surgery may not have been an option for these patients. Also, elderly women do not present with menstrual problems or fibroids, so incidental findings in post-menopausal women should not be expected. A diagnosis

of Sarcoma NOS is frequently given when a patient has not had surgery and this is more common in the elderly. Patients with metastases at diagnosis may only be treated palliatively. As surgery for vaginal cancer tends to be extensive, and may not be more effective than radiotherapy, only a small number of vaginal cancers are treated surgically. Adenosarcoma tends to be less aggressive than tumours such as ESS or leiomyosarcoma and responds well to surgical treatment.

A possible explanation for patients in the most deprived quintile being significantly more likely to be treated surgically (when compared with patients in the least deprived quintile) could be that more patients in the least deprived quintile might have been treated in a private hospital and that their surgery is not recorded in HES. This anomaly requires further investigation as does how the incidence of uterine sarcoma, and fibroids, varies with the patient's ethnicity. It would also be interesting to see how 5-year relative survival rates vary with deprivation status.

Conclusions

This report demonstrates where patients with gynaecological sarcoma were treated surgically between 2001 and 2010, and shows the impact that the Gynaecological Cancer IOG had on the referral of these patients into NHS hospital Trusts which host gynaecological cancer MDTs. The publication of the Gynaecological Cancer IOG in 1999 appears to have had an impact on the proportion of patients referred to a Trust hosting a gynaecological cancer MDT, and there was a reduction in the proportion of patients treated surgically in Trusts which did not host gynaecological and/or sarcoma MDTs. With the data currently available, it is not possible to establish whether patients with gynaecological sarcoma were discussed by a gynaecological cancer MDT or a sarcoma MDT, although this information will be collected from April 2016 onwards.

Gynaecological sarcomas are an exceptionally rare form of malignancy and are often diagnosed incidentally following hysterectomy for suspected fibroids. As such, surgical treatment tends to be undertaken in any hospital with gynaecological services, and not necessarily within a hospital Trust hosting a gynaecological cancer and/or sarcoma MDT. This could to some extent explain why over 180 Trusts surgically treated at least one patient with a gynaecological sarcoma between 2001 and 2010.

Patients with metastases at diagnosis are three times less likely to be treated surgically compared with patients who are metastases free at diagnosis. Patients with less aggressive tumours, such as adenosarcoma, are more likely to be treated surgically. As new datasets such as the National Radiotherapy Dataset (RTDS) and the Systemic Anti-Cancer Treatment (SACT) dataset are further developed and improved, it should be possible to build a more complete picture of the full treatment pathways for patients with gynaecological sarcoma. This is

essential, especially for patients who were not treated surgically, and may have had a palliative intervention.

Further investigation of gynaecological sarcoma treatment pathways is also essential in order to understand why patients with uterine sarcoma have such poor outcomes. Cases of inappropriate management require particular investigation (ie biopsies, hysterectomy in instances where patients already have advanced disease, morcellation of suspected fibroids).

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Appendices

APPENDIX A

GYNAECOLOGICAL CANCER ICD-10 SITE CODES

ICD-10 Group	Description
C51	Malignant neoplasm of vulva
C52	Malignant neoplasm of vagina
C53	Malignant neoplasm of cervix uteri
C54	Malignant neoplasm of corpus uteri
C55	Malignant neoplasm of uterus, part unspecified
C56	Malignant neoplasm of ovary
C57	Malignant neoplasm of other and unspecified female genital organs
C58	Malignant neoplasm of placenta

APPENDIX B

CURATIVE OPCS4 SURGICAL PROCEDURES FOR GYNAECOLOGICAL SARCOMA

The table records all curative procedures for gynaecological sarcomas
Green highlight = Surgical procedures recorded between 2001 and 2010

OPCS4 Code	Description of procedure	No. of occurrences	Performed in % of surgery related admissions
Q074	Total abdominal hysterectomy NEC	1,497	74%
Q221	Bilateral salpingoophorectomy	1,435	71%
Q075	Subtotal abdominal Hysterectomy (does not remove cervix)	106	5%
Q231	Unilateral salpingoophorectomy NEC	89	4%
Q089	Unspecified vaginal excision of uterus	76	4%
T361	Omentectomy	53	3%
T856	Block dissection of pelvic lymph nodes	52	3%
P054	Excision of lesion of vulva NEC	52	3%
P201	Excision of lesion of vagina	24	1%
Q071	Radical Hysterectomy (removes uterus + cervix + vagina)	22	1%
Q072	Abdominal Hysterectomy and excision of periuterine tissue NEC	19	1%
P052	Partial excision of vulva	19	1%
Q079	Unspecified abdominal excision of uterus	18	1%
Q161	Vaginal excision of lesion of uterus	15	1%
Q235	Unilateral oophorectomy NEC	13	1%
Q013	Excision of lesion of cervix ,excision of polyp	12	1%
Q093	Open excision of lesion of uterus NEC	11	1%
Q223	Bilateral oophorectomy, excision of gonads	11	1%
Q222	Bilateral salpingectomy NEC	10	0%
Q232	Salpingoophorectomy of remaining solitary fallopian tube and ovary	9	0%
T331	Open excision of lesion of peritoneum	9	0%
T854	Block dissection of Para aortic lymph nodes	8	0%
X143	Posterior exenteration of pelvis	8	0%
P058	Excision of vulva, other specified	7	0%
P172	Partial colpectomy, partial excision of vagina	7	0%
Q073	Abdominal hysterocolpectomy NEC, Hysterocolpectomy NEC	6	0%
T855	Block dissection of inguinal lymph nodes	6	0%
X148	Other specified clearance of pelvis	4	0%
Q033	Cone biopsy of cervix uteri NEC	3	0%
Q521	Excision of lesion of broad ligament of uterus	3	0%
H334	Anterior resection of rectum and anastomosis NEC	2	0%
H335	Rectosigmoidectomy and closure of rectal stump and exteriorisation of bowel	2	0%
P051	Total excision of vulva	2	0%
Q078	Other specified abdominal excision of uterus	2	0%
Q088	Other specified vaginal excision of uterus	2	0%

OPCS4 Code	Description of procedure	No. of occurrences	Performed in % of surgery related admissions
Q236	Oophorectomy of remaining solitary ovary NEC	2	0%
T362	Excision of lesion of omentum	2	0%
X142	Anterior exenteration of pelvis	2	0%
X149	Unspecified clearance of pelvis	2	0%
H331	Abdominoperineal excision of rectum and end colostomy	1	0%
P011	Clitoridectomy	1	0%
P033	Excision of lesion of Bartholin gland	1	0%
P178	Other specified excision of vagina	1	0%
Q011	Amputation of cervix uteri	1	0%
Q014	Large loop excision of transformation zone	1	0%
Q083	Vaginal hysterocolpectomy NEC	1	0%
Q439	Unspecified partial excision of ovary	1	0%
Q473	Open biopsy of lesion of ovary	1	0%
H332	Proctectomy and anastomosis of colon to anus	0	-
H333	Anterior resection of rectum and anastomosis of colon to rectum using staples	0	-
H336	Anterior resection of rectum and exteriorisation of bowel	0	-
H337	Perineal resection of rectum HFQ	0	-
H338	Other specified excision of rectum	0	-
H339	Unspecified excision of rectum	0	-
P064	Implantation of radioactive substance into vulva	0	-
P171	Total colpectomy	0	-
P179	Unspecified excision of vagina	0	-
Q018	Other specified excision of cervix uteri	0	-
Q031	Knife cone biopsy of cervix uteri	0	-
Q032	Laser cone biopsy of cervix uteri	0	-
Q081	Vaginal hysterocolpectomy and excision of periuterine tissue	0	-
Q082	Vaginal hysterectomy and excision of periuterine tissue NEC	0	-
Q228	Other specified bilateral excision of adnexa of uterus	0	-
Q229	Unspecified bilateral excision of adnexa of uterus	0	-
Q238	Other specified unilateral excision of adnexa of uterus	0	-
Q239	Unspecified unilateral excision of adnexa of uterus	0	-
Q241	Salpingoophorectomy NEC	0	-
Q243	Oophorectomy NEC	0	-
Q438	Other specified partial excision of ovary	0	-
Q478	Other specified other open operations on ovary	0	-
Q491	Endoscopic extirpation of lesion of ovary NEC	0	-
T332	Open destruction of lesion of peritoneum	0	-
T338	Other specified open extirpation of lesion of peritoneum	0	-
T339	Unspecified open extirpation of lesion of peritoneum	0	-
X141	Total exenteration of pelvis	0	-

APPENDIX C

SUPPORTING TABLES FOR FIGURES 1 – 7

Appendix C1 – Supporting data for Figure 1

Year of diagnosis	No of diagnoses	Crude incidence rate*	Age Standardised Rate*	*Lower Confidence Interval*	*Upper Confidence Interval*
2001	263	10.7	10.6	*9.3*	*12.0*
2002	266	10.8	10.6	*9.3*	*12.0*
2003	282	11.4	11.0	*9.7*	*12.4*
2004	280	11.3	10.3	*9.1*	*11.7*
2005	297	12.0	11.7	*10.4*	*13.2*
2006	283	11.4	10.9	*9.6*	*12.3*
2007	288	11.6	10.9	*9.6*	*12.3*
2008	304	12.2	11.2	*10.0*	*12.6*
2009	321	12.8	11.8	*10.5*	*13.2*
2010	283	11.3	10.3	*9.1*	*11.7*

*per million population

Appendix C2 – Supporting data for Figure 2

Age group (years)	No of diagnoses	Age Specific Incidence Rate*
0-4	9	0.29
5-9	1	0.03
10-14	3	0.10
15-19	8	0.25
20-24	16	0.47
25-29	26	0.70
30-34	51	1.33
35-39	110	2.87
40-44	236	6.34
45-49	365	10.43
50-54	353	11.05
55-59	402	13.59
60-64	345	12.68
65-69	242	9.80
70-74	252	11.08
75-79	202	10.32
80-84	121	8.03
85+	125	8.85

*per million population

Appendix C3 – Supporting data for Figure 3

Age group (years)	Record of surgical treatment	No record of surgical treatment	No HES record	Total
0-9	6	4		10
10-19	6	4	1	11
20-29	28	9	5	42
30-39	113	36	12	161
40-49	453	99	49	601
50-59	508	186	61	755
60-69	387	163	37	587
70-79	268	152	34	454
80+	118	104	24	246
Grand Total	**1,887**	**757**	**223**	**2,867**

Appendix C4 – Supporting data for Figure 4

This data table consists of 185 data rows. These data are available on request.

Appendix C5 – Supporting data for Figure 5

	Number of patients treated surgically		
Specialist MDTs hosted within Hospital Trust	2001-2005	2006-2010	Grand Total
G	300	520	820
G/S	121	205	326
S	39	30	69
None	458	356	814
Grand Total	918	1,111	2,029

Appendix C6 – Supporting data for Figure 6

Consultant specialty	No of patients surgically treated
Gynaecology	1,814
Obstetrics	146
Other	42
General surgery	27
Grand Total	**2,029**

Appendix C7 – Supporting data for Figure 7

Characteristic	Odds ratio	p>|z|	LCI	UCI
Age	1.025	<0.01	1.0	1.0
ESS	0.89	0.348	0.7	1.1
Adenosarcoma	0.41	<0.01	0.3	0.6
Sarcoma NOS	2.08	<0.01	1.6	2.7
Other types	1.10	0.630	0.7	1.6
Vulvo-vagina	2.77	<0.01	1.9	4.1
Cervix	1.26	0.366	0.8	2.1
Ovary/other	0.88	0.506	0.6	1.3
Dep quin 2	0.76	0.050	0.6	1.0
Dep quin 3	0.81	0.121	0.6	1.1
Dep quin 4	0.81	0.154	0.6	1.1
Dep quin 5	0.59	<0.01	0.4	0.8
Mets	3.02	<0.01	2.4	3.7
Asian	1.67	0.057	1.0	2.8
Black	1.64	0.058	1.0	2.7
Other/unknown	1.16	0.182	0.9	1.4

LCI = 95% lower confidence interval
UCI = 95% upper confidence interval

Green highlight = significantly more likely to have surgical treatment
Pink highlight = significantly less likely to have surgical treatment