NOGCA | National Oesophago-Gastric Cancer Audit

National Oesophago-Gastric Cancer Audit (NOGCA)

Short Report

Comparison of patients captured by NOGCA and the National Cancer Registration and Analysis Service

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SUMMARY

This short report describes the results of an investigation into how the cohort of patients with epithelial oesophago-gastric (OG) cancer in the National Oesophago-Gastric Cancer Audit compares with the population of OG cancers captured by the English cancer registration process. Specific objectives of the investigation were: (1) to produce a more precise estimate of case ascertainment for the audit, and (2) to describe the characteristics of patients with epithelial cancer who were not being captured by the audit.

The audit dataset contained 61,098 patients and the cancer registration dataset contained 74,679 patients, which gives a crude case ascertainment rate for the audit of 81.8% for the period 2012-18. However, this is a conservative estimate because the audit is restricted to patients with epithelial cancers that have a histological diagnosis. The cancer registration data shows that 69,083 of 74,679 patients (92.5%) had a histological diagnosis over the 2012-18 period. Among the various types of tumours within the cancer registration dataset, non-epithelial cancers corresponded to only 3.1% of patients while another 8.3% had an unknown / unspecified histology (these corresponded mainly to patients diagnosed without biopsy tissue or from death certificates).

Restricting the registration dataset to the audit enrolment criteria produced an estimated case ascertainment for England of 89.6% for the 2012-18 period. The case ascertainment estimate for England for the period covered by the 2019 Annual Report (patients diagnosed between 1 April 2016 and 31 March 2018) was also 89.6%. Eleven of the 19 English Cancer Alliances had an estimated case ascertainment that exceeded 90% for the 2016-18 audit period.

Compared with patients in the audit, those patients who met the audit eligibility criteria but who only appeared in the cancer registration data were more likely to have metastatic disease (or lack cancer stage information), and were older on average. In addition, a smaller proportion of patients whose data were not in the audit survived for 3 months after their cancer diagnosis (61.0% vs 80.2%).

INTRODUCTION

The National Oesophago-Gastric Cancer Audit (NOGCA) is designed to evaluate the care of adult patients who have a histological diagnosis of epithelial oesophago-gastric (OG) cancer in England and Wales. When the audit was first established, it was decided to exclude patients with non-epithelial cancers (such as neuro-endocrine tumours and gastrointestinal stromal tumours) because their clinical management is different from epithelial tumours and because these tumours are comparatively rare. The audit was also restricted to patients with a histologically confirmed diagnosis because information from clinical assessment and imaging alone had been found to be insufficient for accurately diagnosing epithelial OG cancer. These eligibility criteria also meant that clinicians could act more easily upon the audit results.

To date, the method that the NOGCA team used to estimate case ascertainment for English patients has involved comparing the number of patient records submitted to the audit with the number of patients with OG cancer identified in Hospital Episode Statistics (HES), a national database that captures all admissions to English NHS hospitals. The HES database allowed OG cancer patients to be identified on the basis of ICD-10 codes C15 (oesophageal cancer) and C16 (stomach cancer), but it has not allowed either patients with non-epithelial OG cancers or patients without a histological diagnosis to be removed. It has therefore been suggested that the published NOGCA case ascertainment figures have been too low [NOGCA, 2019].

In Summer 2019, the NOGCA team received cancer registration records, as collated by the National Cancer Registration and Analysis Service (NCRAS, Public Health England), to link with the NOGCA patient records submitted by English NHS hospitals. Cancer registration captures all patients with OG cancer (using ICD codes: C15 and C16) but also includes information on the basis of diagnosis (such as histological) and non-epithelial tumours. Consequently, the linked audit-cancer registration dataset enabled an investigation of how the audit cohort of patients with epithelial OG cancer compares with the whole population of OG cancers. This short report describes the results of the investigation. Its specific objectives were: (1) to produce a more precise estimate of case ascertainment, and (2) to describe the characteristics of patients with epithelial cancer who were not being captured by the audit.

The short report was limited to English patients because data on Welsh patients diagnosed with OG cancer are extracted from the Cancer Network Information System Cymru (CaNISC) and submitted centrally instead of by individual NHS hospitals. Consequently, the Welsh cancer registration data does not represent an independent source of data against which to compare the audit patients.

METHODS

The analysis was based on adult patients (aged 18+ years) diagnosed with OG cancer in England between 1 April 2012 and 31 March 2018. The records for these patients were extracted from both the audit and cancer registration databases, and patient identifiers (eg, the NHS number) were used to link the records of patients that appeared in both datasets. The linkage process was undertaken by NCRAS using a file of patient identifiers provided by the NOGCA team. The cancer registration datasets were then returned with the pseudonymised audit identifier added to the registration records of those patients that could be linked.

The file sent to NCRAS by the audit included the identifiers of patients diagnosed with oesophageal high grade dysplasia (HGD) as well as those diagnosed with OG cancer. This was because a proportion of these HGD patients are found to have OG cancer cells within the HGD tissue after treatment, or may also develop cancer subsequently. These patients are not included in this short report because their cancer diagnosis was subsequent to their primary treatment for HGD.

RESULTS

In preparing the datasets for analysis:

- We removed records from the audit dataset related to patients diagnosed with OG cancer in Wales (n=3620) or patients diagnosed with high grade dysplasia (n=2552)
- We removed records from the registration dataset related to patients aged under 18 years (n=5), patients diagnosed in Welsh hospitals (n=27), and any records linked to the audit patients with high grade dysplasia (n=875).

This resulted in the audit dataset containing 61,098 patients and the cancer registration dataset containing 74,679 patients. This gives a crude case ascertainment rate for the audit of 81.8% for the period 2012-18.

As highlighted earlier, this crude ascertainment rate fails to recognise that the audit is restricted to patients with epithelial cancers that have a histological diagnosis. The cancer registration data showed that 69,083 of 74,679 patients (92.5%) had a histological (incl. cytology) diagnosis over the 2012-18 period (Table 1). The largest other group were patients who had a clinical diagnosis with imaging results (5.4%). Patients without a histological diagnosis tended to be older than those diagnosed on that basis; in which NHS trust the patient was diagnosed was also less likely to be recorded. Patients without a diagnosing NHS trust in the registration data are likely to be those who were not discussed by an MDT. Table 2 highlights that patients in the audit tended to survive for longer after diagnosis than those who were not in the audit, regardless of the method of cancer diagnosis.

In total, 57,932 of the cancer registration records were linked to audit records (meaning that the remaining 3,166 audit records and 16,747 registration records could not be linked). Given the audit's eligibility criteria, it is not surprising to find the pattern of linkage between the registration and audit records varied by the method of diagnosis (Table 1). Given that some patients in the audit were not recorded as having a histological diagnosis, it is possible that some patients were either mistakenly included in the audit or had their method of diagnosis misclassified. However, the number of inconsistencies among the linked records was small (1.6%; 905/57,932).

Table 1: Characteristics of patients in cancer registration dataset by method of cancer diagnosis

Method of diagnosis	No. of patients (%)	Age (years) Median, IQR	Patients with unspecified histology	Patients with NHS trust of diagnosis	Patients in audit (%)
Death Certificate	721 (1.0)	84, 76-90	93.5%	6.2%	20 (2.8)
Clinical diagnosis without investigations, tissue	575 (0.8)	83, 74-88	90.4%	69.6%	75 (13.0)
Clinical diagnosis with investig'n, without tissue	3,996 (5.4)	82, 73-88	87.4%	85.3%	746 (18.7)
Cytology	325 (0.4)	71, 60-79	9.8%	99.1%	161 (49.5)
Histology from secondary tumour	1,110 (1.5)	67, 57-76	6.0%	99.5%	519 (46.8)
Histology from primary tumour	67,648 (90.6)	72, 64-80	1.7%	99.7%	56,347 (83.3)
Unknown	304 (0.4)	81, 71-86	80.7%	84.5%	64 (21.1)

Table 2: Proportion of patients alive at 3 and 12 months after diagnosis by method of cancer diagnosis and linked status. Survival estimated using Kaplan-Meier method

Basis of diagnosis	Alive at 3 months		Alive at 1 year	
	Patients in audit	Patients not in audit	Patients in audit	Patients not in audit
Clinical diagnosis without investigations, tissue	63%	25%	17%	9%
Clinical diagnosis with investig'n, without tissue	50%	23%	20%	8%
Cytology	62%	42%	26%	23%
Histology from secondary tumour	61%	49%	21%	19%
Histology from primary tumour	81%	67%	46%	38%
Unknown	70%	35%	26%	16%

The other audit eligibility criterion leads to the exclusion of patients with non-epithelial cancers. These include: neuro-endocrine tumours, gastrointestinal stromal tumour, leiomyosarcoma, leiomyoma lipoma, kaposi sarcoma and malignant melanoma.

Table 3 describes the various types of tumours within the cancer registration dataset. Epithelial cancers dominated, with only 3.1% of patients having a non-epithelial cancer. The patients with an unspecified histology were predominantly among those diagnosed by clinical or death certificate diagnosis. Among the non-epithelial cancers, there were a few instances of the patients being included within the audit. This may reflect the difficulty in classifying the histology in some instances, such as when the tumour contains both malignant adenocarcinoma and neuro-endocrine cells. It might also reflect that the cancer registration process was able to use information collected at various points in the care pathway. In contrast, the audit only requested histology information from the initial diagnosis and from the examination of the removed tumour if the patient had curative surgery. Consequently, hospital staff may have less information to judge whether a patient meets the audit eligibility criteria.

Table 3: Percentage of patients in the cancer registration dataset linked to audit records, by histological types and whether or not the basis of diagnosis was histological

Histology			Patients with histological diagnosis		Patients without histological diagnosis	
	No. of patients	(%)	Total	%patients in audit	Total	%patients in audit
Adenocarcinoma	51,935	(69.5)	51,478	86%	457	38%
Squamous cell carcinoma	12,641	(16.9)	12,536	85%	105	50%
Other epithelial tumours	1,575	(2.1)	1,551	74%	24	13%
Gastrointestinal stromal tumours	814	(1.1)	762	5%	52	6%
Neuro-endocrine tumours	1,417	(1.9)	1,392	26%	25	8%
Other non-epithelial tumours	101	(0.1)	101	23%	0	0%
Unspecified histology	6,196	(8.3)	1,263	57%	4,933	14%
Total	74,679		69,083		5,596	

The histology information can be combined with the method of diagnosis data to refine the denominator for the case ascertainment estimate. In this process, it is assumed that the patients in the audit have been correctly included. Thus, excluding patients with the non-epithelial tumour types from the unlinked NCRAS records reduced the number of unlinked registration records from 16,747 to 10,221 records, and produced an estimated case ascertainment of 89.6% for the 2012-18 period overall (compared with the crude estimate of 81.8%). This figure changes by only a small amount (<1%) when calculated for individual financial years.

The registration-derived case ascertainment estimates for the period covered by the 2019 Annual Report (patients diagnosed between 1 April 2016 and 31 March 2018) was also 89.6% for the whole of England. The increase in case ascertainment across the 19 Cancer Alliances is shown in Figure 1. Eleven of the regions have an estimated case ascertainment that exceeded 90%.

Figure 1: Estimated case ascertainment for the 2016-18 audit period derived using the cancer registration dataset, by English Cancer Alliance. The registration-based figures are compared against the figures based on Hospital Episode Statistics as reported in the 2019 Annual Report

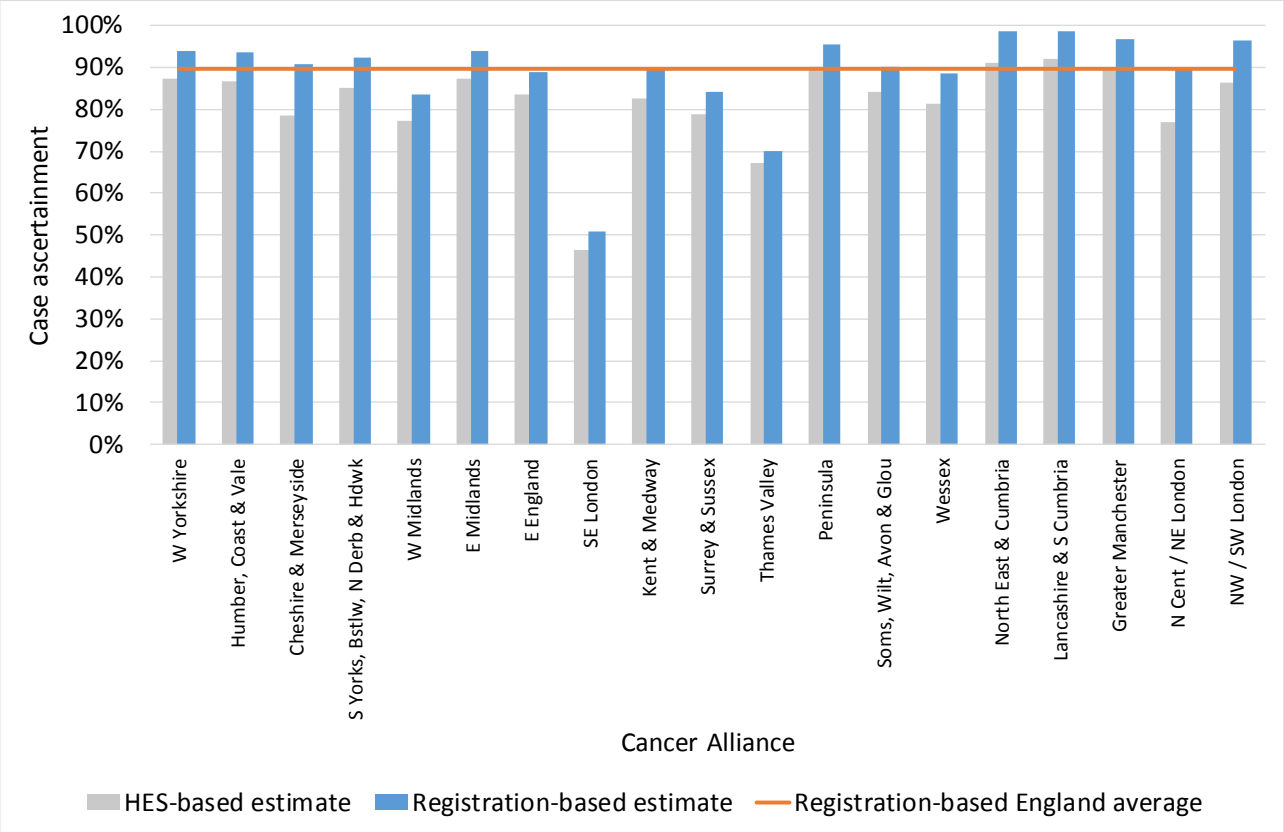

Table 4 describes the characteristics of the patients who meet the audit eligibility criteria, grouped by whether or not the registration records could be linked with audit records. The unlinked cancer registration records highlight that the patients diagnosed between April 2012 and March 2018 whose data were not submitted to the audit:

- Were older on average
- Were more likely to have stomach cancer
- Contained a greater proportion of patients with stage 4 (metastatic disease) or unknown stage
- Died sooner after their cancer diagnosis

Table 4: Characteristics of patients with linked and unlinked cancer registration records for patients diagnosed with OG cancer between April 2012 and March 2018 in England

Patient characteristic	Unlinked patients in registration data	Linked patients in registration and audit data	Unlinked patients in audit data
No. of patients	10,221	57,932	3,166
Patient sex			
Male	65.0%	68.9%	66.3%
Female	35.0%	31.1%	33.7%
Age group (years)			
Under 60	13.5%	16.3%	15.3%
60-69	21.0%	25.2%	25.2%
70-79	28.9%	32.3%	34.1%
80 & over	36.7%	26.3%	25.5%
Tumour site			
Oesophagus	53.6%	60.7%	n/a
Stomach	46.4%	39.3%	n/a
Histology			
Adenocarcinoma	72.3%	76.4%	73.5%
Squamous cell	18.5%	18.5%	16.9%
Other	9.2%	5.1%	9.6%
TNM stage			
1	6.4%	9.3%	n/a
2	6.7%	14.4%	n/a
3	12.7%	26.7%	n/a
4	35.8%	31.8%	n/a
Unknown	38.4%	17.8%	n/a
Proportion of patients alive after diagnosis			
At 91 days	61.0%	80.2%	n/a
At 183 days	41.8%	61.4%	n/a
At 365 days	29.3%	45.8%	n/a

CONCLUSION

The aim of the analysis described in this short report was to investigate how the NOGCA cohort of patients with epithelial OG cancer compares with the population of OG cancers captured by the registration process, with a particular focus on the implications for estimating the case ascertainment of the audit.

In the 2019 NOGCA Annual Report, the reported case ascertainment for English NHS trusts was estimated to be 82.5%. The cancer registration-derived estimate was 89.6% for the same period (patients diagnosed between 1 April 2016 and 31 March 2018), which confirms the suggestion in the 2019 Annual Report that the estimated case ascertainment was likely to be too low because it was not possible to limit the HES data to histologically-confirmed epithelial cancers. It is also worth adding that the HES-based denominator was inflated by patients who were initially diagnosed with high grade dysplasia and who later developed OG cancer.

The main conclusion from these results is for the audit team to improve the method used to estimate case ascertainment by using the cancer registration data instead of HES. However, while the approach works well at a national level, the level of agreement between the NHS trust of diagnosis recorded in the audit and cancer registration datasets was found to be variable for the 2012-18 audit period. Overall, there was

agreement between the datasets for 92% of the linked patient records but, for three Cancer Alliances, the level of agreement was below 85%. The maximum level of agreement in any Alliance was 97% of the linked patient records. Therefore, as part of the process of adopting an approach based on cancer registration data, the audit will explore how to increase the alignment of the two datasets.

In calculating the case ascertainment figures, it was assumed that the 3,166 patients whose audit records could not be linked to cancer registration data were contained within the 10,221 unlinked registration records. This was considered reasonable given the comprehensive nature of the cancer registration data, and the small chance that NHS trusts could upload data to the audit on patients who did not have OG cancer. It is quite plausible that errors in the patient identifiers (eg, mistyped NHS number) have prevented the linkage between the two datasets, particularly as the method of linkage was deterministic. To explore the validity of this assumption, a simple analysis was undertaken to assess the extent to which we could match records in the two unlinked portions of the audit and registration datasets on four shared pieces of information: patient age, patient area of residence (ie, Lower Super Output Area), date of cancer diagnosis, and NHS trust of diagnosis. In the first step of the analysis, a probabilistic matching algorithm was used on the records that had been linked by NCRAS (using the patient identifiers). This found that the four pieces of information resulted in the same records being linked for 98% of patients. When the matching algorithm was applied to the unlinked records, matches were identified in the registration dataset for 26% of the unlinked audit records. These exploratory results suggest it might be possible to decrease the number of missed matches, and further work using a greater number of shared data items in the matching algorithm is warranted.

Another interesting aspect of this work was the identification of patients diagnosed with HGD in the cancer registration data. The combination of audit and registration records could provide greater insight into both how many of these patients have cancer at the time of their HGD diagnosis and also how many develop cancer subsequently. This issue was investigated in previous NOGCA Annual reports using linked audit-HES records but the interpretation of the results was limited by the lack of a definitive date of cancer diagnosis. This had to be inferred from the first occurrence of the ICD-10 codes for oesophageal and stomach cancer (C15 and C16). The linked audit-registration records will overcome this issue and enable more precise results on patterns of care for HGD patients to be published in the future.

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REFERENCE

National Oesophago-Gastric Cancer Audit (NOGCA). Annual Report 2019. London: Royal College of Surgeons of England, 2019. Available from: https://www.nogca.org.uk/reports/2019-annual-report/