

# BMJ Open Coding of Barrett's oesophagus with high-grade dysplasia in national administrative databases: a population-based cohort study

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## ABSTRACT

**Objectives** The International Classification of Diseases 10th Revision (ICD-10) system used in the English hospital administrative database (Hospital Episode Statistics (HES)) does not contain a specific code for oesophageal high-grade dysplasia (HGD). The aim of this paper was to examine how patients with HGD were coded in HES and whether it was done consistently.

**Setting** National population-based cohort study of patients with newly diagnosed with HGD in England. The study used data collected prospectively as part of the National Oesophago-Gastric Cancer Audit (NOGCA). These records were linked to HES to investigate the pattern of ICD-10 codes recorded for these patients at the time of diagnosis.

**Participants** All patients with a new diagnosis of HGD between 1 April 2013 and 31 March 2014 in England, who had data submitted to the NOGCA.

**Outcomes measured** The main outcome assessed was the pattern of primary and secondary ICD-10 diagnostic codes recorded in the HES records at endoscopy at the time of diagnosis of HGD.

**Results** Among 452 patients with a new diagnosis of HGD between 1 April 2013 and 31 March 2014, Barrett's oesophagus was the only condition coded in 200 (44.2%) HES records. Records for 59 patients (13.1%) contained no oesophageal conditions. The remaining 193 patients had various diagnostic codes recorded, 93 included a diagnosis of Barrett's oesophagus and 57 included a diagnosis of oesophageal/gastric cardia cancer.

**Conclusions** HES is not suitable to support national studies looking at the management of HGD. This is one reason for the UK to adopt an extended ICD system (akin to ICD-10-CM).

## INTRODUCTION

It is well recognised that Barrett's oesophagus may progress to oesophageal adenocarcinoma through a dysplasia carcinoma sequence.<sup>1</sup> The risk of progression to adenocarcinoma depends on the presence and severity of dysplasia. In non-dysplastic Barrett's, the risk is only 0.1% per year<sup>2</sup> and the disease can be managed by surveillance alone. If high-grade

## Strengths and limitations of this study

- Study used data collected prospectively for all patients diagnosed with high-grade dysplasia (HGD) of the oesophagus in England linked with Hospital Episode Statistics (HES), and therefore provides representative results about the current coding of HGD in HES.
- Case ascertainment of HGD cases by the audit is uncertain, but there is no reason to believe that the cases submitted to the audit would differ systematically in how they were recorded in HES compared with those not submitted.
- The study used data submitted by hospitals to a central database and data recorded in HES. It was not possible to validate data from either source against medical records.

dysplasia (HGD) is present, the risk of progression increases to 5.6% per year<sup>3</sup> and active treatment is recommended.<sup>4</sup>

Since April 2012, patients with a new diagnosis of oesophageal HGD in England have been eligible for inclusion in the National Oesophago-Gastric Cancer Audit (NOGCA). Hospitals prospectively collect data on patient characteristics, the results of the diagnostic endoscopy, planned treatment modality and pathology of the tissue after endoscopic or surgical resection.

A challenge for the Audit has been to derive the number of HGD patients in England, and thereby monitor case ascertainment. For patients diagnosed with oesophageal cancer, it is possible to derive the number of cases using the Hospital Episode Statistics (HES) administrative database.<sup>5</sup> HES uses the International Classification of Diseases 10th Revision (ICD-10) disease classification<sup>6</sup> to capture clinical conditions, and this contains clear codes for cancer diagnoses. Unfortunately, the standard ICD-10 system is not



specific for different types of Barrett's oesophagus, and it is unclear how hospitals are using ICD-10 codes to record a diagnosis of HGD. The aim of this study is to explore which diagnostic codes are currently being used to record oesophageal HGD in HES and to assess the consistency of this coding.

## METHODS

This study used a linked dataset that combined information from the records of patients in the NOGCA and HES. Patients were eligible for the study if they were diagnosed with oesophageal HGD in England between 1 April 2013 and 31 March 2014, and we were able to link their record in the NOGCA with records contained in an extract of HES that covered all hospital admissions between April 2012 and March 2015. Patient records were linked by matching the patient's National Health Service number (a unique identifier for each UK resident) held in each dataset.

Each HES record describes the episode of care during which a patient is under the care of a hospital consultant. Patient conditions are described using a primary diagnosis and up to 19 secondary diagnoses, and a record can hold up to 24 procedures (coded using the Office of Population, Censuses and Surveys (OPCS)-4 Classification of Interventions and Procedures<sup>7</sup>).

For each patient in NOGCA, we identified all HES records relating to that patient. Using the date of diagnosis of HGD in the NOGCA record, we identified the HES episode with a start date closest to this date, and selected this record for analysis. Using predefined OPCS codes (see online supplementary appendix 1), any endoscopic procedures the patient had during this episode

were identified. Patients were dropped from analysis if they did not have any endoscopic procedures recorded during this episode. Furthermore, a few patients had more than one episode with the same start date; in these cases, the record with most information relating to endoscopic procedures performed was selected.

Using this cohort of HGD patients, we then examined the pattern of primary and secondary ICD-10 diagnostic codes in the HES records, describing the common combinations of codes in terms of whether Barrett's oesophagus or other related pathology was recorded. The analysis was performed using STATA V.14 (Statacorp).

The study was exempt from the UK National Research Ethics Committee approval as it involved the secondary analysis of existing data for service evaluation. Section 251 approval was obtained for the collection of the personal health data from the Ethics and Confidentiality Committee.

## RESULTS

The linked NOGCA-HES dataset contained 474 patients diagnosed with oesophageal HGD between 1 April 2013 and 31 March 2014. Among these, 22 patients did not have an endoscopy procedure recorded in the HES episode nearest the date of HGD diagnosis and these patients were excluded, leaving 452 patients for analysis.

The frequent combinations of diagnostic codes entered into the HES records are summarised in [table 1](#). There were 293 (64.8%) patients who had Barrett's oesophagus recorded in any diagnosis field, and this was the primary diagnosis recorded for 225 patients. Unexpectedly, analysis found that 59 (13.1%) patients had no record of any oesophageal pathology recorded in HES.

**Table 1** Diagnostic fields recorded in HES records among patients diagnosed with high-grade dysplasia of the oesophagus in the national oesophagogastric cancer audit

Oesophageal codes recorded		Frequency	(%)	Number with code for Barrett's oesophagus	Number without code for Barrett's oesophagus
K227	Barrett's oesophagus with no additional codes	200	44	200	NA
C15x	Malignant neoplasm of oesophagus	57	13	24	33
C160	Malignant neoplasm of gastric cardia				
D001	Carcinoma in situ oesophagus	13	3	6	7
D130	Benign neoplasm of oesophagus	16	4	6	10
D377	Neoplasm of uncertain/unknown behaviour in oral cavity and digestive organs				
K221	Oesophageal ulcer	29	6	14	15
K20x, K21x K22x*, K23x	Other benign oesophageal pathology not otherwise accounted for	78	17	43	35
	No oesophageal pathology recorded	59	13	NA	59
	Overall	452		293	159

\*Excluding K227 (Barrett's oesophagus) and K221 (oesophageal ulcer).



For 200 (68.3%) of the 293 patients with a diagnosis of Barrett's, this was the only diagnosis recorded, highlighting the fact that, in many cases, no additional code relating to oesophageal pathology was recorded to indicate evidence of dysplasia. For the 93 patients who had another diagnostic code recorded in addition to Barrett's, the most frequent codes were for benign oesophageal pathology (43) and upper gastrointestinal cancer/cancer in situ (36).

## DISCUSSION

Barrett's oesophagus is a known premalignant condition for oesophageal cancer,<sup>1</sup> and the incidence of oesophageal cancer and Barrett's oesophagus has risen steeply over the recent years.<sup>8</sup> While the management of this group of patients can be examined using national registries or clinical audits, a weakness of this approach is having confidence all eligible cases are being captured.

In other situations, a common approach to determine the case ascertainment of a registry is to compare it to the data in a national administrative hospital dataset. In England, this study demonstrates that the HES database cannot fulfil this function in relation to patients with oesophageal HGD because the coding in HES records is variable. The study found that a third of HGD patients reported to the NOGCA had no HES record of a diagnosis of Barrett's oesophagus at the time of diagnosis of HGD. Furthermore, where a diagnosis of Barrett's oesophagus was recorded, HES cannot be used to identify those patients who had the disease complicated by the presence of HGD. It was unexpected to find 57 patients with a diagnosis of cancer recorded in HES. This suggests that some patients either had a HGD record incorrectly submitted to the NOGCA (instead of a cancer record if both HGD and cancer were present on the initial biopsy or the cancer was incorrectly coded in HES). We explored this issue by reviewing the pathology records of patients with HGD who had an endoscopic mucosal resection (EMR). Among the 25 patients with a diagnosis of cancer in HES and an EMR pathology record in the NOGCA, 9 (36%) of these patients had no record of malignancy, which suggests a cancer diagnosis was incorrectly recorded in HES. Finally, 13.1% of patients had no diagnosis codes related to oesophageal pathology at all recorded in HES.

This study suffers from various limitations. First, as this study used data collected for a national audit, it was not possible to access individual patient records to confirm the accuracy of submitted data, in terms of date of diagnosis and pathology results. Consequently it is possible if the date of diagnosis of HGD submitted to the audit was inaccurate, then the corresponding HES episode selected for analysis may not have been the right one. Second, as previously mentioned, we were unable to confirm whether the diagnosis of cancer recorded in HES at the time of diagnosis of HGD was in fact correct on original pathology reports.

Despite these limitations, the results highlight a significant problem for any national study looking at the management of HGD in England. The lack of a robust method for identifying these patients in a routine hospital database means it is not possible to estimate the incidence of the disease and the case ascertainment of national studies. This is of concern because early results from the NOGCA dataset showed that a third of patients with HGD were managed by surveillance alone,<sup>9</sup> and it may be that this figure is even higher due to the effect of selection bias if the cases submitted to NOGCA are not representative of the national population.

The main reason for this situation concerns the lack of a specific code for Barrett's oesophagus with HGD in the standard ICD-10 diagnosis codes. This limitation is not unique to ICD-10. For example, there is also no specific code for Barrett's oesophagus with HGD within SNOMED. However, other countries have addressed this issue by producing a modified version of ICD-10, such as the ICD-10 Clinical Modification (CM) codes in the USA. The ICD-10-CM system of coding allows for up to seven characters to be recorded for each diagnostic field, incorporating greater detail about the diagnosis, for example, disease aetiology, anatomic site and laterality. In particular, the K22.7 code for Barrett's oesophagus has been augmented to include codes for Barrett's oesophagus with dysplasia (K22.719) and for Barrett's oesophagus with high-grade and low-grade dysplasia (LGD) specifically (K22.711 and K22.710, respectively).<sup>10</sup>

In the UK, the introduction of ICD-11 is planned for 2018. This will be an improvement because there are codes to distinguish between non-dysplastic Barrett's oesophagus (EB90) and Barrett's with dysplasia (EB91). The ability to further distinguish HGD from LGD within ICD-10-CM is important given the updated BSG guidelines recommend the treatment of confirmed LGD as well.<sup>4</sup> With the rising incidence of oesophageal adenocarcinoma, it is vital that there is a means to identify cases of oesophageal dysplasia in HES, so that the incidence can be monitored and national studies can be done to ensure it is being appropriately treated. We suspect this weakness is not limited to this clinical area, and consequently, we suggest that there would be considerable benefit to the UK if it adopted its own modification of the ICD-11 system for use in national databases such as HES.

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