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## Coding of Barrett's oesophagus with high grade dysplasia in national administrative databases

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3 **Coding of Barrett's oesophagus with high grade dysplasia in national administrative**  
4 **databases**  
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49 **WORD COUNT**

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**ABSTRACT**

Objectives: The 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 HGD patients 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 in order 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<sup>st</sup> April 2013 and 1<sup>st</sup> April 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<sup>st</sup> April 2013 and 1<sup>st</sup> April 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 contained combinations of various conditions, including Barrett's oesophagus (n=93), oesophageal / gastric cardia cancer (n=57), and oesophageal ulcer (n=14).

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).

## STRENGTHS AND LIMITATIONS

- Barrett's Oesophagus with high grade dysplasia (HGD) is an important pre-cursor to oesophageal cancer, but it is unclear how hospitals are coding the condition with ICD-10 in national hospital databases.
- The study compares the data submitted to Hospital Episode Statistics (HES) from multiple organisations and so provides representative results on the coding of HGD in national databases.
- Routine hospital databases like HES might be missing ICD-10 codes or contain misclassification errors. It was not possible to validate Hospital Episodes Statistics coding against medical records.

## FUNDING

This research received no specific grant from any funding agency in the public, commercial or not-for profit sectors.

## INTRODUCTION

It is well recognised that Barrett's oesophagus may progress to oesophageal adenocarcinoma through a dysplasia carcinoma sequence (1). 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 (2) and the disease can be managed by surveillance alone. If high grade dysplasia (HGD) is present, the risk of progression increases to 5.6% per year (3) and active treatment is recommended (4).

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 (5). HES uses the ICD-10 disease classification (6) 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 when patients have 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 National Oesophago-Gastric Cancer Audit (NOGCA) and Hospital Episode Statistics (HES). Patients were eligible for the study if they were diagnosed with oesophageal HGD in England between 1st April 2013 and 31st March 2014, and we were able to link their record in the NOGCA with records contained in an extract of HES that covered all admissions between April 2012 and March 2015. Patient records were linked by matching the patient's National Health Service (NHS) 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 OPCS-4 Classification of Interventions and Procedures (7)). For each patient, we identified all HES records and then selected from these the episode whose start date was closest to the date of the HGD diagnosis recorded in NOGCA. Any endoscopic procedures occurring in these episodes were then identified (see appendix 1). If two episodes had the same start date, 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 related pathology was recorded.

## 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 a diagnosis of Barrett's oesophagus recorded in any diagnosis field, and this was the principal diagnosis in 225 records. Barrett's was the only condition entered in 200 (44.2%) HES records, highlighting that, in many cases, no additional code relating to oesophageal pathology was recorded. Unexpectedly, the HES records of 59 patients (13.1%) contained no codes for pathology related to the oesophagus.

The remaining 193 patients were described with a variety of oesophageal conditions, including the specific diagnoses of: malignant neoplasm of oesophagus or gastric cardia (n=57), carcinoma in situ (n=6) and oesophageal ulcer (n=14). Overall, around half of the

HES records included Barrett's oesophagus recorded (93 of 193), and this proportion did not vary much across the different conditions.

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

Oesophageal codes recorded		Frequency	(%)	No. with code for Barrett's Oesoph	No. without code for Barrett's Oesoph
K227	Barrett's Oesophagus with no additional codes	200	44%	200	n/a
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	Other benign oesophageal pathology not otherwise accounted for	78	17%	43	35
K22x*, K23x					
	No oesophageal pathology recorded	59	13%	n/a	59
	<b>Overall</b>	<b>452</b>		<b>293</b>	<b>159</b>

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

## DISCUSSION

Barrett's oesophagus is a known pre-malignant condition for oesophageal cancer (1), and the incidence of oesophageal cancer and Barrett's oesophagus has risen steeply over recent years (8). 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 Hospital Episode Statistics 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 HGD patients 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. Secondly, as previously mentioned, we were unable to confirm whether the



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3 diagnosis of cancer recorded in HES at the time of diagnosis of HGD was in fact correct on  
4 original pathology reports.  
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8 Despite these limitations, the results highlight a significant problem for any national study  
9 looking at the management of HGD in England. The lack of a robust method for identifying  
10 these patients in a routine hospital database means it is not possible to estimate the  
11 incidence of the disease and the case ascertainment of national studies. This is of concern  
12 because early results from the NOGCA dataset showed that a third of patients with HGD  
13 were managed by surveillance alone (9), and it may be that this figure is even higher due to  
14 the effect of selection bias if the cases submitted to NOGCA are not representative of the  
15 national population.  
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19 The main reason for this situation concerns the lack of a specific code for Barrett's  
20 oesophagus with HGD in the standard ICD-10 diagnosis codes. This limitation is not unique  
21 to ICD-10. For example, there is also no specific code for Barrett's oesophagus with HGD  
22 within SNOWMED. However, other countries have addressed this issue by producing a  
23 modified-version of ICD-10, such as the ICD-10-CM codes in the US . The ICD-10-CM system  
24 of coding allows for up to 7 characters to be recorded for each diagnostic field,  
25 incorporating greater detail about the diagnosis e.g. disease aetiology, anatomic site and  
26 laterality. In particular, the K22.7 code for Barrett's oesophagus has been augmented to  
27 include codes for Barrett's oesophagus with dysplasia (K22.719) and for Barrett's  
28 oesophagus with high grade and low grade dysplasia specifically (K22.711 and K22.710,  
29 respectively).  
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33 In the UK, the introduction of ICD-11 is planned for 2018. This will be an improvement  
34 because there are codes to distinguish between non dysplastic Barrett's oesophagus (EB90)  
35 and Barrett's with dysplasia (EB91). However, this will still be inadequate for studies of HGD,  
36 not least because low grade dysplasia can regress. We suspect this weakness is not limited  
37 to this clinical area, and consequently, we suggest that there would be considerable benefit  
38 to the UK if it adopted its own modification of the ICD-11 system for use in national  
39 databases such as HES.  
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HES data were made available by the NHS Health and Social Care Information Centre (copyright © 2012, reused with permission of the Health and Social Care Information Centre. All rights reserved).

## CONFLICT OF INTEREST

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests.

## DATA SHARING STATEMENT

No additional unpublished data available from the study.

## AUTHOR CONTRIBUTIONS

1. **Chadwick G:** Main author involved in all stages
2. **Varagunam M:** Conception and design, analysis and interpretation of data, critical revision of the article, and final approval of article.
3. **Brand C:** Conception and design, interpretation of data, critical revision of the article, and final approval of article.
4. **Riley S:** Conception and design, interpretation of data, critical revision of the article, and final approval of article.
5. **Maynard N:** Conception and design, interpretation of data, critical revision of the article, and final approval of article.
6. **Crosby T:** Conception and design, interpretation of data, critical revision of the article, and final approval of article.
7. **Michalowski J:** Conception and design, critical revision of the article, and final approval of article.

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3 **8. Cromwell D:** Conception and design, analysis and interpretation of data, critical  
4 revision of the article, and final approval of article  
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Appendix 1: OPCS-4 codes used to identify endoscopic procedures in HES

	Procedure	Specific OPCS-4 codes for procedures under endoscopic control	Non-specific OPCS-4 codes for procedure, only considered if they occurred in the same episode as a definite endoscopic procedure
Endoscopic procedure	Diagnostic OGD	G16 G19.1/8/9 G21.4 G45	
	Ablation	G14.2/3/5/7 G17.2/3 G42.2 G43.2/3/4/5/7	Y08 Y11.4 Y13.1/4/6
	Resection	G14.1/6 G17.1 G42.1 G43.1	
	Other therapeutic OGD	G14.8/9 G15.8/9 G17.8/9 G18.8/9 G42.8/9 G43.8/9 G44.8/9 G46.8/9	
	Dilatation	G15.2/3/5 G18.2/3/5 G44.3/6	Y40
	Stent insertion	G15.4/6/7 G18.4 G21.5 G44.1	G11.2/8/9 Y02.1/2/8/9 Y14.1/2/3/4/8/9

STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

	Item No	Recommendation
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract <b>Yes</b>
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found <b>Yes</b>
<b>Introduction</b>		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported <b>Yes</b>
Objectives	3	State specific objectives, including any prespecified hypotheses <b>Yes</b>
<b>Methods</b>		
Study design	4	Present key elements of study design early in the paper <b>Yes</b>
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection <b>Yes</b>
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <b>Yes</b> (b) For matched studies, give matching criteria and number of exposed and unexposed <b>N/A</b>
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable <b>Yes</b>
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group <b>Yes</b>
Bias	9	Describe any efforts to address potential sources of bias <b>N/A</b>
Study size	10	Explain how the study size was arrived at <b>Yes</b>
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why <b>Yes</b>
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding <b>Yes</b> (b) Describe any methods used to examine subgroups and interactions <b>N/A</b> (c) Explain how missing data were addressed <b>N/A</b> (d) If applicable, explain how loss to follow-up was addressed <b>N/A</b> (e) Describe any sensitivity analyses <b>N/A</b>
<b>Results</b>		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed <b>Yes</b> (b) Give reasons for non-participation at each stage <b>N/A</b> (c) Consider use of a flow diagram <b>N/A</b>
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders <b>N/A</b> (b) Indicate number of participants with missing data for each variable of interest <b>Yes</b> (c) Summarise follow-up time (eg, average and total amount) <b>N/A</b>
Outcome data	15*	Report numbers of outcome events or summary measures over time <b>N/A</b>
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were

		adjusted for and why they were included <b>Yes</b>
		(b) Report category boundaries when continuous variables were categorized <b>N/A</b>
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period <b>N/A</b>
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses <b>Yes</b>
<b>Discussion</b>		
Key results	18	Summarise key results with reference to study objectives <b>Yes</b>
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias <b>N/A</b>
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence <b>Yes</b>
Generalisability	21	Discuss the generalisability (external validity) of the study results <b>Yes</b>
<b>Other information</b>		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based <b>Yes</b>

\*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.

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

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<b>Primary Subject Heading</b>:	Gastroenterology and hepatology
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**ABSTRACT**

Objectives: The 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 HGD patients 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 in order 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<sup>st</sup> April 2013 and 1<sup>st</sup> April 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<sup>st</sup> April 2013 and 1<sup>st</sup> April 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).

## STRENGTHS AND LIMITATIONS

- 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 to 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.

## FUNDING

This research received no specific grant from any funding agency in the public, commercial or not-for profit sectors.

## INTRODUCTION

It is well recognised that Barrett's oesophagus may progress to oesophageal adenocarcinoma through a dysplasia carcinoma sequence (1). 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 (2) and the disease can be managed by surveillance alone. If high grade dysplasia (HGD) is present, the risk of progression increases to 5.6% per year (3) and active treatment is recommended (4).

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 (5). HES uses the ICD-10 disease classification (6) 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 National Oesophago-Gastric Cancer Audit (NOGCA) and Hospital Episode Statistics (HES). Patients were eligible for the study if they were diagnosed with oesophageal HGD in England between 1st April 2013 and 31st 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

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3 National Health Service (NHS) number (a unique identifier for each UK resident) held in each  
4 dataset.  
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8 Each HES record describes the episode of care during which a patient is under the care of a  
9 hospital consultant. Patient conditions are described using a primary diagnosis and up to 19  
10 secondary diagnoses, and a record can hold up to 24 procedures (coded using the OPCS-4  
11 Classification of Interventions and Procedures (7)).  
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17 For each patient in NOGCA , we identified all HES records relating to that patient. Using the  
18 date of diagnosis of HGD in the NOGCA record, we identified the HES episode with a start  
19 date closest to this date, and selected this record for analysis. Using pre-defined OPCS codes  
20 (see Appendix 1), any endoscopic procedures the patient had during this episode were  
21 identified. Patients were dropped from analysis if they did not have any endoscopic  
22 procedures recorded during this episode. Furthermore, a few patients had more than one  
23 episode with the same start date; in these cases the record with most information relating  
24 to endoscopic procedures performed was selected.  
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33 Using this cohort of HGD patients, we then examined the pattern of primary and secondary  
34 ICD-10 diagnostic codes in the HES records, describing the common combinations of codes  
35 in terms of whether Barrett's oesophagus or other related pathology was recorded. The  
36 analysis was performed using STATA 14 (Statacorp, College Station, Texas, USA).  
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42 The study was exempt from the UK National Research Ethics Committee approval as it  
43 involved the secondary analysis of existing data for service evaluation. Section 251 approval  
44 was obtained for the collection of the personal health data from the Ethics and  
45 Confidentiality Committee.  
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## 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.

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).

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

Oesophageal codes recorded		Frequency	(%)	No. with code for Barrett's Oesophagus	No. without code for Barrett's Oesophagus
K227	Barrett's Oesophagus with no additional codes	200	44%	200	n/a
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	Other benign oesophageal pathology not otherwise accounted for	78	17%	43	35
K22x*, K23x					
	No oesophageal pathology recorded	59	13%	n/a	59
<b>Overall</b>		<b>452</b>		<b>293</b>	<b>159</b>

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

## DISCUSSION

Barrett's oesophagus is a known pre-malignant condition for oesophageal cancer (1), and the incidence of oesophageal cancer and Barrett's oesophagus has risen steeply over recent years (8). 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 Hospital Episode Statistics 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 HGD patients 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. Secondly, as previously mentioned, we were unable to confirm whether the

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3 diagnosis of cancer recorded in HES at the time of diagnosis of HGD was in fact correct on  
4 original pathology reports.  
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8 Despite these limitations, the results highlight a significant problem for any national study  
9 looking at the management of HGD in England. The lack of a robust method for identifying  
10 these patients in a routine hospital database means it is not possible to estimate the  
11 incidence of the disease and the case ascertainment of national studies. This is of concern  
12 because early results from the NOGCA dataset showed that a third of patients with HGD  
13 were managed by surveillance alone (9), and it may be that this figure is even higher due to  
14 the effect of selection bias if the cases submitted to NOGCA are not representative of the  
15 national population.  
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19 The main reason for this situation concerns the lack of a specific code for Barrett's  
20 oesophagus with HGD in the standard ICD-10 diagnosis codes. This limitation is not unique  
21 to ICD-10. For example, there is also no specific code for Barrett's oesophagus with HGD  
22 within SNOWMED. However, other countries have addressed this issue by producing a  
23 modified-version of ICD-10, such as the ICD-10-CM codes in the US . The ICD-10-CM system  
24 of coding allows for up to 7 characters to be recorded for each diagnostic field,  
25 incorporating greater detail about the diagnosis e.g. disease aetiology, anatomic site and  
26 laterality. In particular, the K22.7 code for Barrett's oesophagus has been augmented to  
27 include codes for Barrett's oesophagus with dysplasia (K22.719) and for Barrett's  
28 oesophagus with high grade and low grade dysplasia (LGD) specifically (K22.711 and  
29 K22.710, respectively) (10).  
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45 In the UK, the introduction of ICD-11 is planned for 2018. This will be an improvement  
46 because there are codes to distinguish between non dysplastic Barrett's oesophagus (EB90)  
47 and Barrett's with dysplasia (EB91). The ability to further distinguish HGD from LGD within  
48 ICD-10-CM is important given the updated BSG guidelines recommend the treatment of  
49 confirmed LGD as well (4). With the rising incidence of oesophageal adenocarcinoma, it is  
50 vital that there is a means to identify cases of oesophageal dysplasia in HES, so that the  
51 incidence can be monitored and national studies can be done to ensure it is being  
52 appropriately treated. We suspect this weakness is not limited to this clinical area, and  
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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.

## ACKNOWLEDGEMENTS

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HES data were made available by the NHS Health and Social Care Information Centre (copyright © 2012, reused with permission of the Health and Social Care Information Centre. All rights reserved).

## CONFLICT OF INTEREST

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests.

## DATA SHARING STATEMENT

No additional unpublished data available from the study.

## AUTHOR CONTRIBUTIONS

1. **Chadwick G:** Main author involved in all stages
2. **Varagunam M:** Conception and design, analysis and interpretation of data, critical revision of the article, and final approval of article.
3. **Brand C:** Conception and design, interpretation of data, critical revision of the article, and final approval of article.
4. **Riley S:** Conception and design, interpretation of data, critical revision of the article, and final approval of article.
5. **Maynard N:** Conception and design, interpretation of data, critical revision of the article, and final approval of article.
6. **Crosby T:** Conception and design, interpretation of data, critical revision of the article, and final approval of article.

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7. **Michalowski J:** Conception and design, critical revision of the article, and final approval of article.
8. **Cromwell D:** Conception and design, analysis and interpretation of data, critical revision of the article, and final approval of article

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Appendix 1: OPCS-4 codes used to identify endoscopic procedures in HES

	Procedure	Specific OPCS-4 codes for procedures under endoscopic control	Non-specific OPCS-4 codes for procedure, only considered if they occurred in the same episode as a definite endoscopic procedure
Endoscopic procedure	Diagnostic OGD	G16 G19.1/8/9 G21.4 G45	
	Ablation	G14.2/3/5/7 G17.2/3 G42.2 G43.2/3/4/5/7	Y08 Y11.4 Y13.1/4/6
	Resection	G14.1/6 G17.1 G42.1 G43.1	
	Other therapeutic OGD	G14.8/9 G15.8/9 G17.8/9 G18.8/9 G42.8/9 G43.8/9 G44.8/9 G46.8/9	
	Dilatation	G15.2/3/5 G18.2/3/5 G44.3/6	Y40
	Stent insertion	G15.4/6/7 G18.4 G21.5 G44.1	G11.2/8/9 Y02.1/2/8/9 Y14.1/2/3/4/8/9

STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

	Item No	Recommendation
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract <b>Yes 1-2</b>
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found <b>Yes 2</b>
<b>Introduction</b>		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported <b>Yes 4</b>
Objectives	3	State specific objectives, including any prespecified hypotheses <b>Yes 4</b>
<b>Methods</b>		
Study design	4	Present key elements of study design early in the paper <b>Yes 4</b>
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection <b>Yes 4</b>
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <b>Yes 4-5</b> (b) For matched studies, give matching criteria and number of exposed and unexposed <b>N/A</b>
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable <b>Yes 5</b>
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group <b>Yes 4-5</b>
Bias	9	Describe any efforts to address potential sources of bias <b>N/A</b>
Study size	10	Explain how the study size was arrived at <b>Yes 4</b>
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why <b>N/A</b>
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding <b>N/A</b> (b) Describe any methods used to examine subgroups and interactions <b>N/A</b> (c) Explain how missing data were addressed <b>N/A</b> (d) If applicable, explain how loss to follow-up was addressed <b>N/A</b> (e) Describe any sensitivity analyses <b>N/A</b>
<b>Results</b>		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed <b>Yes 5</b> (b) Give reasons for non-participation at each stage <b>Yes 5</b> (c) Consider use of a flow diagram <b>N/A</b>
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders <b>N/A</b> (b) Indicate number of participants with missing data for each variable of interest <b>Yes 5</b> (c) Summarise follow-up time (eg, average and total amount) <b>N/A</b>
Outcome data	15*	Report numbers of outcome events or summary measures over time <b>N/A</b>
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were

		adjusted for and why they were included <b>Yes 6</b>
		(b) Report category boundaries when continuous variables were categorized <b>N/A</b>
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period <b>N/A</b>
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses <b>Yes 6</b>
<b>Discussion</b>		
Key results	18	Summarise key results with reference to study objectives <b>Yes 7</b>
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias <b>3, 8-9</b>
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence <b>Yes 9</b>
Generalisability	21	Discuss the generalisability (external validity) of the study results <b>Yes 9</b>
<b>Other information</b>		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based <b>Yes 3</b>

\*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.