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OBSERVATIONAL RESEARCH

Utilising multiple discharge coding will improve identification of patients with giant cell arteritis: a retrospective analysis of a hospital discharge dataset

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Abstract

To determine whether the discharge diagnosis codes used within tertiary hospitals accurately identified patients with Giant Cell Arteritis (GCA), as determined by expert opinion at 6 months. The study was performed across three major hospitals within Perth, Western Australia. Patients with an International Classification of Diseases (ICD) code for GCA (M31.5 and M31.6) at discharge on first inpatient presentation were identified. Review of case notes, discharge summaries, letters, pathology, and imaging results were undertaken. The percentage of patients with an ICD code for GCA at initial discharge with confirmed GCA by expert opinion at 6 months (as the anchor diagnosis) was calculated. As validation of the anchor diagnosis, the percentage who fulfilled the 2022 ACR/EULAR criteria was also calculated, the number of hospital discharges per patient with an ICD code for GCA was calculated, to determine if multiple discharges with an ICD code for GCA increased the specificity of the ICD coding. 93 out of 157 admissions with an ICD for GCA were identified as a first inpatient presentation. At 6 months follow up, 65.6%, 95 CI [55.0%, 75.1%] had confirmed GCA by expert opinion. 88.2%, 95 CI [79.8%, 93.9%] met the 2022 ACR/EULAR criteria for GCA. The specificity of the ICD coding increased with increasing number of discharges– 67.4% with single episode, 80% with two episodes, and 100% with three or more episodes ($p=0.1373$). Only 43.8%, 95 CI [26.4%, 62.3%] of patients who did not have GCA had an alternative diagnosis provided. 31.3%, 95 CI [16.1%, 50.0%] of patients who did not have GCA still have the GCA diagnosis listed in their subsequent clinical records and discharge summaries. Only 2/3rds of those patients with an initial discharge ICD code for GCA were found to have confirmed GCA at follow-up. This poor correlation between the ICD coding and confirmed diagnosis of GCA will impact the quality of data extracted from administrative health datasets for epidemiological and longitudinal studies. Selecting patients with two or more GCA coded episodes could improve the homogeneity of the cohort for recruitment into GCA studies, but a larger sample size study is required.

Keywords Giant cell arteritis · Temporal arteritis · Temporal artery biopsy · ACR/EULAR criteria · Administrative health data · Epidemiology

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Introduction

Giant cell arteritis (GCA) is a large vessel vasculitis that affects older people, with a peak incidence in the seventh decade [1]. GCA can be a devastating disease, as delays in therapy can result in the complications of blindness, stroke, or death [2]. Once diagnosed, GCA management is a complicated balance of the risks and benefits of long-term immunosuppression in often elderly and vulnerable people [3]. As a relatively uncommon condition, research efforts have lagged other more common inflammatory conditions. Administrative data sets can be a source of large amounts of data to study uncommon diseases such as GCA. These data sets rely on ICD codes to identify diagnosed cases of the disease of interest, and the quality of the research produced is therefore dependant on the accuracy of diagnostic coding in the administrative dataset. In addition, many countries, including Australia, uses ICD codes for mortality and morbidity analysis, clinical research, epidemiological studies, and healthcare safety and quality studies [4]. The ICD codes for GCA are extracted from the discharge diagnosis at the time of patients' initial presentation. These are often inaccurate as they may be provisional diagnosis, without access to the full investigative results, and potentially made by non-experts, or without reference to a diagnostic algorithm. Using provisional diagnosis of GCA at time of discharge have the potential to compromise the integrity of GCA databases.

GCA can be a difficult diagnosis to ascertain, as it is associated with a variety of clinical presentations [1]. Histological confirmation with biopsy of the temporal artery (TAB) is often sought, but it has a reported sensitivity of 15–77% [5, 6],. Ultrasonography, CT, MRI, and PET all have a potential role in the diagnosis of GCA, with the diagnostic accuracy dependant on local expertise, the clinical phenotype and prior duration of steroid treatment [7]. Ultrasound has a sensitivity of 68% and specificity of 91% [8]; CT angiogram has a sensitivity of 73% and specificity of 78% [9]; MRI has a sensitivity of 73% and sensitivity of 88% [9]; while PET scan has a sensitivity of 71% and specificity of 91% for diagnosing GCA [7]. The low sensitivity of biopsy and imaging techniques make the diagnosis of GCA challenging. Another difficulty in diagnosis of GCA is the lack of diagnostic criteria [10]. Whilst classification criteria for GCA were developed by the ACR in 1990, it is designed to maximise specificity at the expesne of sensitivity to create a homogenous cohort for clinical research [8]. The 1990 ACR GCA classification criteria has been shown to perform poorly when used as diagnostic criteria [10]. This unmet need for diagnostic criteria in GCA has led to the Diagnostic and Classification Criteria for Vasculitis (DCVAS) initiative [11] and the development of 2022 ACR/EULAR classification criteria for GCA [12]. These new criteria incorporated investigative imaging (ultrasound, angiography, PET) unlike the older classification criteria [12]. Whilst they remain classification criteria, and not diagnostic criteria, they demonstrated greater sensitivity while maintaining similar specificity to the older criteria [12]. The 2022 ACR/EULAR criteria proved to be adequate in diagnosis of patients with suspected GCA in routine clinical care [13].

Many studies still consider the gold standard diagnosis of GCA to be the clinical opinion determined by an expert at 6 months [7, 8, 14, 15]. Given that the gold standard diagnosis requires longitudinal follow-up, reliance on discharge diagnosis provided by administrative health databases to identify cohorts for epidemiological studies may confer significant inaccuracies [16]. Effective and efficient planning, monitoring, and evaluation of health services depend on accurate and reliable data for health statistics [17]. Therefore, inaccuracies in coded clinical data can have far-reaching consequences [17].

The aims of this study were (1) to determine the performance of a discharge ICD code of GCA compared to a confirmed diagnosis of GCA by expert assessment at 6 months; (2) to determine the performance of a discharge ICD code of GCA compared to the 2022 ACR/EULAR criteria at time of discharge; (3) to explore whether increased number of ICD GCA coded episodes in a patient over time correlated with a clinical diagnosis of GCA at 6 months; and (4) to determine the proportion of misdiagnosed cases at first discharge that were corrected at subsequent discharges.

Methods

A retrospective observational study was performed at three major sites: Royal Perth Hospital (RPH), Fiona Stanley Hospital (FSH), and Fremantle Hospital (FH). This study was registered through the Governance Evidence Knowledge Outcomes database as a Quality Activity with the QA Number 40,632 for RPH, and 50,395 for FSH and FH.

Patients

Patients admitted to hospital between January 2016 and February 2021 and given a discharge diagnosis of GCA were identified by primary or secondary discharge ICD codes M31.5 (Giant Cell Arteritis with Polymyalgia Rheumatica) and M31.6 (Giant Cell Arteritis without Polymyalgia Rheumatica). Admission data was extracted from the hospital administrative database by the respective Clinical Coding Departments.

These data included patients with inpatient admissions and day-unit admissions. The inpatient admissions included

patients who presented to hospital for GCA related disorders, either first presentations, or readmissions of GCA flares. The day-unit admissions captured patient who presented for elective temporal artery biopsies, or tocilizumab/methylprednisolone infusions, which are all same-day cases.

Main outcome variable

Data provided included gender, age, discharge diagnosis and length of stay. Supplemental data for this cohort was obtained from electronic hospital discharge summaries and outpatient clinic letters to assess additional clinical aspects.

For each patient with first discharge from inpatient admission for GCA, relevant clinical details from the period of hospitalisation were assessed to determine whether the patient met the 2022 ACR/EULAR criteria at discharge. Results from temporal artery biopsy and imaging (CDUS, PET scan, CT angiogram and/or MR angiogram) were analysed to assess the proportion of diagnosed cases supported by objective evidence. The end point to determine final diagnosis was the expert opinion on outpatient follow-up at 6 months, as documented by a GCA expert specialists (rheumatologist, ophthalmologist or neurologist) in the clinic correspondence, as is the precedence in the literature [13].

Other variables

For the de-diagnosed cohort, the percentage allocated an alternative diagnosis was determined. Medical records were also reviewed longitudinally to ascertain the total number of discharges for an individual that were assigned a ICD-10 coding of GCA and whether the diagnosis of GCA was removed from their medical history in future documentation.

Statistical analysis

The statistical analysis was largely descriptive. Statistical values are presented with a 95% confidence interval. The statistical significance of utilising coding frequency in identifying patients with GCA is compared with Fisher's exact test.

To ensure consistency, the data was collected by a single reviewer. The data was kept in a secure folder within a password-protected computer behind a firewall, and data was anonymised to ensure patient confidentiality.

Results

A total of 157 cases were identified with a discharge ICD-10 coding of GCA between January 2016 and January 2021. Of the 157 presentations, 105 were inpatient admissions, and 52 were day-unit admissions.

Of the 105 inpatient admissions, 94 were initial presentations of suspected GCA, and the remaining 11 were readmissions for flares of previously diagnosed GCA. The 94 patients with first presentation of suspected GCA are included in analysis assessing accuracy of the ICD discharge diagnosis compared to the clinical diagnosis at 6 months. Out of these 94 patients, 93 had follow up data to confirm GCA status. The remaining 1 had unknown status as he passed away prior to follow up and therefore excluded from the study.

Performance of the ICD coding compared to clinical diagnosis at 6 months

Of the 93 patients who had a discharge ICD-10 code of GCA, 61/93 (65.6%), 95 CI [55.0%, 75.1%] had GCA diagnosis confirmed by expert opinion at 6-month follow-up. Out of these 61 who had confirmed GCA, 58/61 (95.1%), 95 CI [86.3%, 99.0%] met the ACR/EULAR criteria, and 3/61 (4.9%), 95 CI [1.0%, 13.7%] did not meet the ACR/EULAR criteria (Fig. 1).

Performance of the ICD coding compared to 2022 ACR/EULAR criteria

Of the 93 patients who had a discharge GCA ICD-10 code, 82/93 (88.2%), 95 CI [79.8%, 93.9%] met the ACR/EULAR criteria (score of ≥ 6), and 11/93 (11.8%), 95 CI [6.1%, 20.2%] did not meet the criteria, as shown on Fig. 1. Of the 82 who met the criteria, 58/82 (70.7%), 95 CI [59.6%, 80.3%] have GCA, and 24/82 (29.3%), 95 CI [19.7%, 40.4%] did not. Of the 11 who did not meet the ACR/EULAR criteria, 3/11 (27.3%), 95 CI [6.0%, 61.0%] of them were eventually diagnosed with GCA, while the remaining 8/11 (72.7%), 95 CI [39.0%, 94.0%] did not have GCA.

Analysis on coding frequency

157 GCA related ICD coded discharges in 126 patients were analysed with regards to the number of ICD-10 codes of GCA and clinical diagnosis at 6 months. 93 ICD coded discharges were multi day admission. 52 ICD coded discharges were same-day admissions, consisting of 39 temporal artery biopsies and 13 medication infusions. Figure 2 summarises the breakdown of these cases. 105 patients have one coding frequency (equivalent to 105 ICD codes); 15 patients had

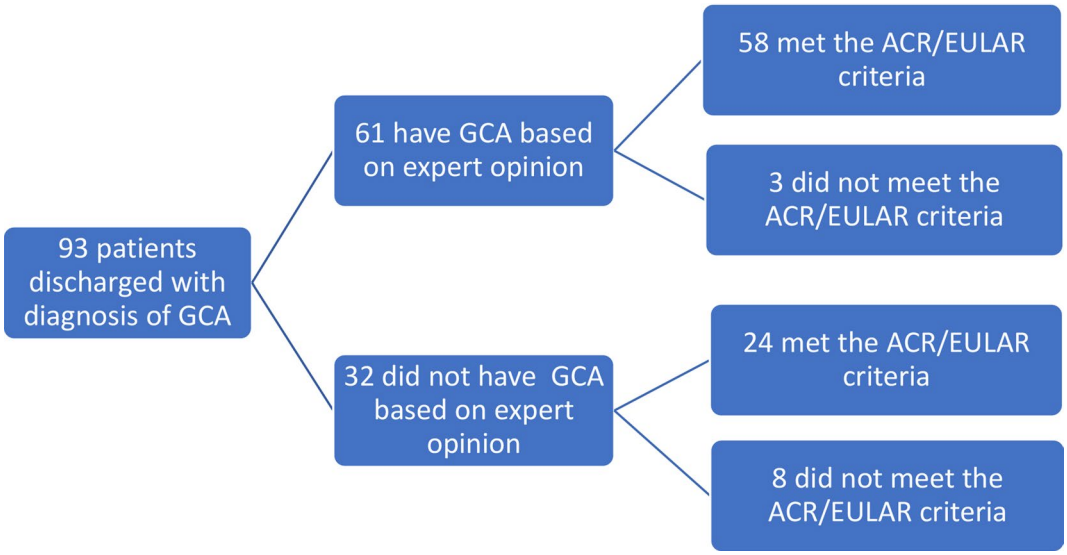

Fig. 1 Outcome of 94 new discharge diagnosis of GCA

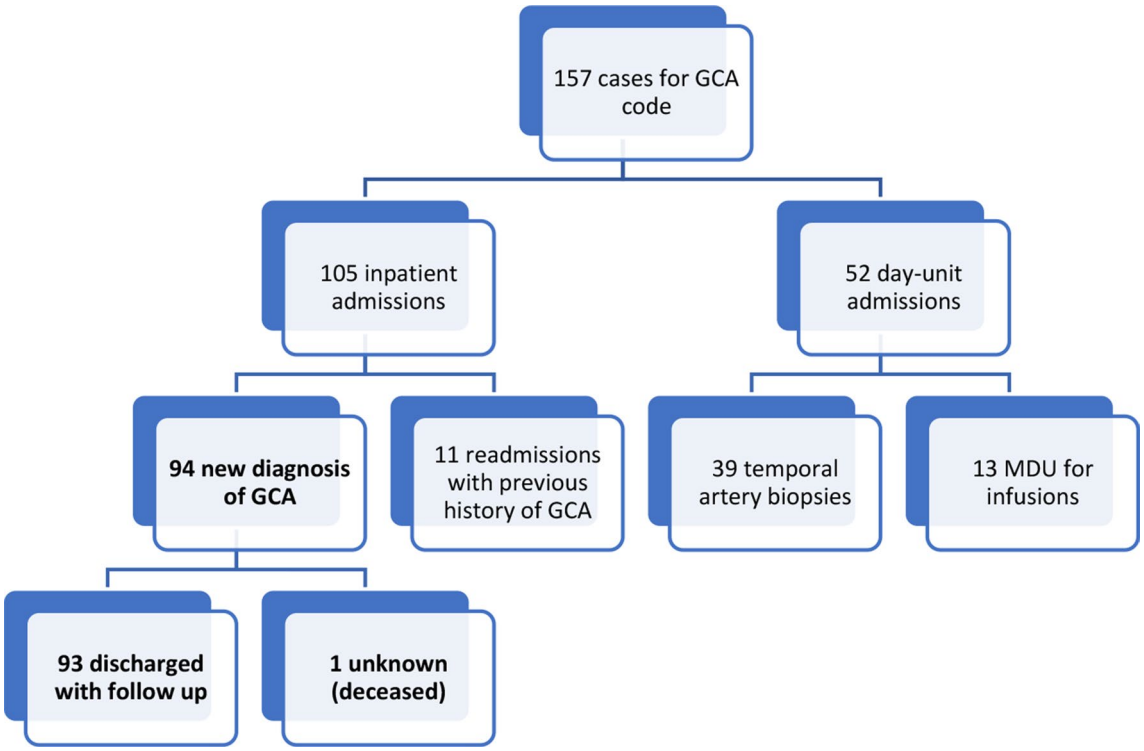

Fig. 2 Breakdown of the study cohort

two coding frequency (equivalent to 30 ICD codes), and 6 patients with three or more coding frequency (equivalent to 22 ICD codes).

Out of the 105 patients with one ICD-10 code of GCA, 19 have insufficient documentation to be included in the analysis. From the remaining 86 patients with one ICD-10 code of GCA, 58 (67.4%) had GCA, 28 (32.6%) did not have GCA. Out of the 15 who had two ICD-10 code of GCA, 12 (80%) have GCA and 3 (20%) did not. Of the 6 patients with three or more ICD-10 code of GCA, 100% had GCA ($p=0.1373$) (Figure 3).

Correction of misdiagnosed cases

Of the 32 patients who were found to not have GCA at 6-month follow-up, 14 (43.8%), 95 CI [26.4%, 62.3%] had

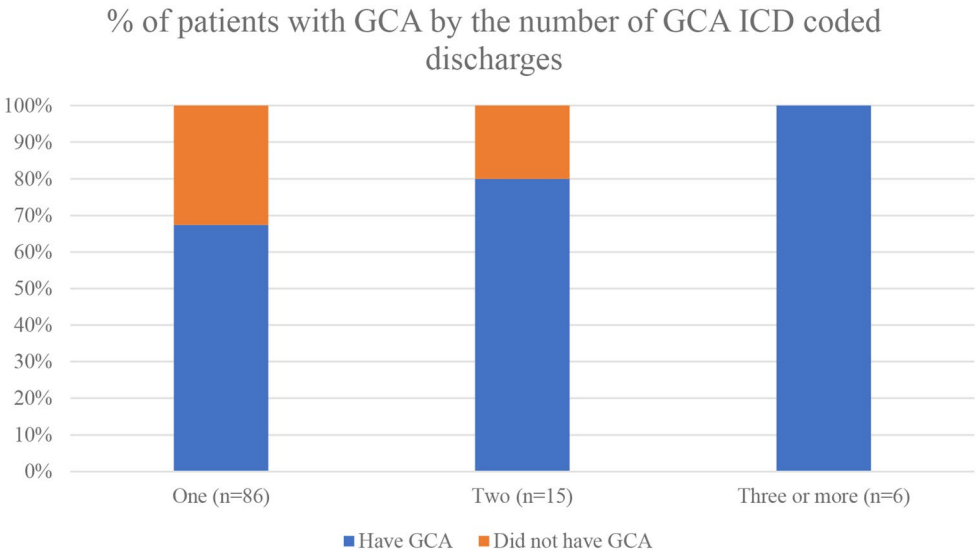

Fig. 3 Graph comparing outcome of diagnosis of GCA versus inpatient coding frequency

Table 1 Alternative diagnosis provided in negative cases

Alternative diagnosis	Number of cases
Diabetic maculopathy	1
Macular degeneration	1
Presyncope from 1st degree heart block	1
Occipital neuralgia/ trigeminal neuralgia	2
Meningioma	1
Intraocular vascular thrombus	1
Multiple sclerosis	1
Aspergillosis	1
Cervical spondylosis	1
Sinusitis	2
PMR without GCA	2
No alternative diagnosis provided	18
Total negative cases	**32**

an alternative diagnosis provided (see Table 1), while the remaining 18 (56.3%), 95 CI [37.7%, 73.6%] did not have documentation of alternative diagnosis. At 6 months follow-up, 10/32 (31.3%), 95 CI [16.1%, 50.0%] did not have their medical history amended to remove GCA from their subsequent clinical records and discharge summaries, despite expert opinion being that they did not have GCA. 14/32 (43.8%), 95 CI [26.4%, 62.3%] had the diagnosis successfully removed from subsequent documentation of medical history. The remaining 8/32 (25%), 95 CI [11.5%, 43.4%] had no further documentation from public hospital databases for review.

Discussion

Administrative datasets are frequently used in epidemiological studies [4]. However, it is important to understand the limitations of such data. Since administrative datasets rely largely on discharge diagnosis, this study sought to determine the accuracy of a discharge diagnosis of GCA (ICD code M31.5 and M31.6) as compared to expert diagnosis of GCA at 6 months. This study found that only 65.6%, 95 CI [55.0%, 75.1%] have confirmed GCA based on expert opinion at six months follow up although 88.2%, 95 CI [79.8%, 93.9%] of the patients discharged with a diagnosis of GCA fulfilled the 2022 ACR/EULAR criteria for GCA.

We used a clinician diagnosis of GCA at 6 months as the anchor, which is generally recognised as the current gold standard [7, 8, 14, 15], although other definitions exist. The lack of a perfect test to diagnose GCA as well as lack of standardised definition for GCA diagnosis has resulted in heterogenous data within databases used in epidemiological studies [18]. For example, hospital-based studies often only include biopsy-proven GCA cases, whereas population-based studies often include a clinical diagnosis [18]. Therefore, results may vary depending on which definition of GCA is used. In clinical practice, early diagnosis of GCA is key, and the index of suspicion of GCA should be high, so that treatment can be started promptly to prevent irreversible ischaemic complications [19]. However, this may lead to a preliminary diagnosis of GCA at discharge, though often it is only through the composite results of multimodal imaging, TAB, laboratory parameters and assessment of clinical features over time through which final diagnosis or de-diagnosis is made. Undoubtedly, efforts should be made to objectively secure the diagnosis wherever possible to avoid unnecessary treatment, which may also lead to a revised diagnosis prior to the 6-month mark [15]. It is not surprising that a third of patients with an initial ICD code of GCA are de diagnosed by an expert at 6 months.

The 2022 ACR/ EULAR were utilised to give some validity to the expert opinion, which is by nature subjective. 58 of 61 with a clinical diagnosis of GCA at 6 months met the 2022 ACR/EULAR criteria at first discharge, suggesting that the classification criteria have a high sensitivity of

95.1% in our cohort. Interestingly, although classification criteria are created with specificity in mind, in this study 24/32 were falsely classified as GCA by the 2022 ACR/EULAR criteria, suggesting poor specificity of 25%. Such classification criteria are for research purposes only, as they excluded symptoms of extracranial GCA [20]. Indeed, a retrospective case series has shown that 25.7% of patients with positive TAB did not meet the initial 1990 ACR criteria, further highlighting that these criteria are not intended for diagnostic purposes [20, 21].

This study demonstrated that multiple ICD-10 codes for GCA in a patient raises the probability of a that patient for having GCA. In this study, the chance of identifying a patient with GCA is 67.4% with one ICD-10 codes for GCA, 80% with two ICD-10 codes for GCA, and 100% with three or more ICD-10 codes for GCA ($p=0.1373$). The multiple inpatient coding frequencies could be due to readmission for GCA flares, outpatient TAB, or for day infusions of methylprednisolone or tocilizumab. Therefore, to increase the accuracy of studies utilising administrative data, the case ascertainment definition could require multiple discharges with an ICD-10 codes for GCA. This method has been proposed by Almutairi et al. (2021) in utilising rheumatoid arthritis (RA) diagnostic code with biologic infusion codes, to improve accuracy of administrative health data for identifying patients with RA [22]. This is a simple intervention to improve the validity of case identification in GCA studies using administrative data [22]. It would most like produce a more homogenous population in patient selection for GCA studies. However, a further study with a larger sample size is required to achieve statistical significance.

After 6 months follow up, less than half of those patients de diagnosed with GCA were given an alternative diagnosis, the most common being sinusitis and occipital/ trigeminal neuralgia. This does however attest to the protean and often ill-defined presentations that may lead clinicians to mistakenly suspect GCA [23]. Concerningly, a third of these patients still had GCA listed in their medical record and subsequent discharge summaries, indicating a high rate of persistent inaccuracies in medical databases over time. If the diagnosis of GCA had been disproven after expert review, efforts should be made to remove this diagnosis from the database and medical records. The implications of having GCA perpetually remain in their medical history could result in future episodes being mistaken for GCA flares and thus commencing unnecessary immunosuppression. Practical strategies include involving clinicians to actively remove the GCA diagnosis from their medical history; sending a letter to their general practitioner (GP), and to coding department to remove this diagnosis; and empowering the patients to remind other clinicians that they do not have GCA.

A strength of this study is that it took into account patients with a diagnosis of GCA by expert opinion, not just those with a positive TAB or imaging. It also included patients with extracranial phenotypes of GCA. Therefore, it had more accurate representation of the confirmed GCA cases, not just those with a positive TAB. The use of expert opinion is the most reliable tool for diagnosis of GCA [7, 8, 14, 15].

The limitations of this study are its small sample size and retrospective design. Because the data in this study were collected by reviewing medical records and discharge summaries, there was information bias due to missing medical records. It also relies on the accuracy of clinician documentation and discharge summaries which are collected retrospectively. In addition, the ACR/EULAR score was calculated based on symptoms documented in the medical records. As such, there would be high assessor variability, instead of having a select number of trained assessors. This was difficult to address in a retrospective study, thus creating a need for a prospective study design in future.

Conclusion

Across three major Western Australian hospitals, 88.2%, 95 CI [79.8%, 93.9%] of the discharge ICD code for GCA met the 2022 ACR/EULAR criteria, but only 65.6%, 95 CI [55.0%, 75.1%] of patients are found to have GCA at follow-up. A high proportion (31.3%), 95 CI [16.1%, 50.0%] of de-diagnosed cases did not have the GCA diagnosis removed from their medical record, perpetuating inaccuracy. This may affect the quality of epidemiological studies that use data extracted from hospital coding departments. Utilising multiple coding frequencies of GCA will improve the quality of the administrative dataset studies by capturing a higher proportion of patients with confirmed GCA.

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Data availability An in-house statistician was consulted for statistical data analysis. No external editing support was required. No part of this manuscript, including the text and graphics, are copied, or published elsewhere in whole or in part. There was no use of AI for writing and editing of the article. We are willing to provide Open Data Sharing upon request, pending approval from our institution. This study has also been presented as a poster to the following congress: Dermawan A, Murdoch J, Keen H (2023). ARA-P47. An analysis of

hospital discharge coding for giant cell arteritis shows high proportion of patients meet the 2016 revised ACR classification criteria at time of discharge, but one-third did not have GCA based on diagnostic tests and expert opinion at follow-up visits. ARA congress 2023, Hobart, Tasmania, Australia. https://doi.org/10.1111/imj.16057. Dermawan A (2023). KP-121 An analysis of hospital discharge coding for Giant Cell Arteritis shows high proportion of patients meeting the rACR criteria, but one-third do not have GCA. Lupus & KCR 2023, Seoul, Korea.

Declarations

Ethical approval This study was registered through the Governance Evidence Knowledge Outcomes database as a Quality Activity with the QA Number 40632 for RPH, and 50395 for FSH and FH. This has been approved by the ethics committee on 14 September 2023. There is also a publishing reference number 295 issued by the hospital safety & quality division.

Conflict of interest There is no conflict of interest among all co-authors.

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