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## **Coding accuracy for Parkinson disease hospital admissions: implications for healthcare planning in the UK**

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**Key words:** Parkinson's disease; Hospital Episode Statistics; service evaluation; clinical coding.

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## **Abstract**

**Objectives:** Hospital Episode Statistics data are used for healthcare planning and hospital reimbursements. Reliability of these data is dependent on the accuracy of individual hospitals reporting Secondary Use Services (SUS) which includes hospitalisation. The number and coding accuracy for Parkinson's disease hospital admissions at a tertiary centre in Birmingham was assessed.

**Study Design:** Retrospective, routine-data-based study

**Methods:** A retrospective electronic database search for all Parkinson's disease patients admitted to the tertiary hospital over a 4 year period (2009-2013) was performed on the SUS database using International Classification of Disease (ICD-10) codes, and on the local inpatient electronic prescription database, Prescription and Information Communications System (PICS), using medication prescriptions. Capture-recapture methods were used to estimate the number of patients and admissions missed by both databases. **Results:** From the two databases, between July 2009 and June 2013, 1,068 patients with Parkinson's disease accounted for 1,999 admissions. During these admissions Parkinson's disease was coded as a primary or secondary diagnosis. 91% of these admissions were recorded on the SUS database. Capture-recapture methods estimated that the number of Parkinson's disease patients admitted during this period was 1,127 patients (95% confidence interval: 1,107 -1,146). A supplementary search of both SUS and PICS was undertaken using the hospital numbers of these 1,068 patients. This identified another 479 admissions. SUS database under-estimated Parkinson's disease admissions by 27% during the study period. **Conclusion:** The accuracy of disease coding is critical for healthcare policy planning and must be improved. If the under-reporting of Parkinson's disease admissions on the SUS database is repeated nationally, expenditure on PD admissions in England is under-estimated by approximately £61 million per year.

## **Introduction**

Parkinson's disease is characterised by a progressive motor syndrome, along with non-motor features such as dementia, anxiety, depression, and autonomic dysfunction. These symptoms reduce patient quality of life and lead to increased use of health care resources.[1] Individuals with the disease have higher hospitalisation rates and longer hospital stays than their age-matched counterparts.[2] The resulting economic burden from Parkinson's disease hospitalisation is substantial.[3] Low et al, recently evaluated the cost of Parkinson's disease hospitalisation using the Hospital Episodes Statistics (HES) in England, and reported a total National Health Service (NHS) expenditure of £907 million over a four year period. [3] It is crucial that metrics relating to hospital episodes are accurate, since these data are used for hospital reimbursements and health care planning. [4] Chronic conditions are often underreported during hospital admissions where the condition may not be the primary cause of admission. [5]

In this study, we estimated the number of Parkinson's disease admissions to a large Birmingham hospital, and assessed the coding accuracy of the admissions.

## **Methods**

This service evaluation was approved and registered with the University Hospital Birmingham (UHB) audit department. The hospital is a large tertiary centre in the United Kingdom's second largest city with a capacity of 1,213 inpatient beds. [6] Data extraction was performed by the hospital informatics department.

The Secondary Uses Services (SUS) is a database where all data pertaining to health resource use in NHS trusts in England are stored. [4] We searched SUS for Parkinson's disease admissions during the period 1st July 2009 to 30th June 2013. Admissions where Parkinson's disease was recorded as a primary or secondary diagnosis were identified from this database

using the International Classification of Diseases 10 (ICD-10) codes G20 and F02.3 for Parkinson's disease and Parkinson's disease dementia, respectively. The UHB electronic inpatient Prescribing Information and Communications System (PICS) database, stores information on medications prescribed during hospital admissions. We searched PICS database for all admissions where Parkinson's disease medications (Table 1) were prescribed during the study period.

We performed a number of quality assurance checks on the data. Firstly, since Parkinson's disease is less prevalent in younger age groups, [7] we reviewed all patient records for admissions identified from our search of SUS and PICS where the patient age was under 40 years, and excluded those who had diagnoses other than Parkinson's disease. Secondly, since dopaminergic drugs used for treating Parkinson's disease are also used in other conditions such as restless legs syndrome and dopa-responsive dystonia, we examined all patient case notes for admissions identified from the PICS database where Parkinson's disease medications were prescribed and excluded those with other diagnoses.

For all admissions identified from the SUS database using the ICD-10 codes, G20 and F02.3, and admissions from the PICS database based on Parkinson's disease medication, patient hospital numbers were obtained. A further (supplementary) search of the two databases was then undertaken using these hospital numbers to identify additional hospital admissions missed by the SUS and PICS criteria, but still occurring in the evaluation period.

We applied capture-recapture methods [8] to estimate the number of Parkinson's disease patients who were missed by searching both SUS and PICS databases. Capture-recapture is a recognised method for estimating population sizes or completeness of data sources and assumes that the available sources are independent and do not identify the entire population being studied.[8, 9] The original use of this method was in estimating the size of animal

populations.[9, 10] The method involved capturing as many animals as possible in an initial survey, labelling them, and releasing them back into the population.[9, 10] This was followed by a second survey (termed recapture), where the animals were also counted and labelled.[9, 10] The numbers of animals in the first and second survey and those appearing in both were then used to estimate the size of the missing population.[9, 10] In our study, the number of patients found in SUS only, PICS only, and those appearing in both databases were used for estimating the number of missing patients. Chao's lower bound method which provides a reliable estimation of the total population size was used. [9]

The same capture-recapture analysis was also applied to the number of Parkinson's disease admissions identified from SUS and PICS databases. Admissions obtained from the supplementary search using hospital numbers were not included in the capture-recapture analysis, as this was not an independent source of admissions.

### ***Assessing the coding error rate***

The coding error rate was defined as the proportion of Parkinson's disease admissions not recorded in the SUS database. The denominator was the sum of all admissions identified by the PICS, SUS, and hospital number search. Admissions that appeared in both SUS and PICS databases were counted once only. The numerator was the number of Parkinson's disease admissions not appearing in the SUS database. Descriptive analyses of the type of patients (age, gender) and information on the admissions which included type of admission: elective (planned) or non-elective (emergency), reasons for admissions, and admitting specialty, were performed.

## **Results**

### ***Exclusions***

2,300 possible Parkinson's disease admissions were identified from SUS and PICS databases over the four year period. 16 admissions for patients below the age of 40 years who had diagnoses other than Parkinson's disease (dopa-responsive dystonia, pituitary tumours, and drug-induced Parkinsonism) were excluded (figure 1). After reviewing case notes for patients who had admissions identified from the PICS database, 285 admissions for patients who did not have Parkinson's disease were also excluded.

### ***Numbers of patients***

PICS and SUS database identified 1,068 PD patients during the four year study period (figure 2): median age 75 years (interquartile range 67-82) and 59% male. Capture-recapture methods estimated that 59 patients were missed by both databases, meaning that over the four year period an estimated 1,127 (95% confidence interval: 1,107 to 1,146) Parkinson's disease patients were admitted to UHB. Therefore, SUS database missed an estimated 130 patients (range: 110 to 149 missed patients).

### ***Numbers of admissions***

SUS database identified 1,811 admissions during the study period. Of these, 1,053 admissions appeared in both databases, 758 were in SUS only, and 188 admissions were in PICS only. Therefore, in total, 1,999 admissions were identified from the two databases. Capture-recapture methods estimated that 212 admissions were missed by SUS and PICS searches, meaning that over the four year period, there were an estimated 2,211 (95% confidence interval: 2,169 to 2,252) admissions.

A supplementary search of both databases using the 1,068 patient hospital numbers obtained from the initial SUS and PICS searches, identified an additional 479 admissions. For these admissions, no Parkinson's disease ICD-10 code was recorded on SUS and no Parkinson's

disease medications were prescribed on PICS (Table 2). Therefore, when the three search criteria (SUS, PICS and hospital numbers) were combined, a total of 2,478 Parkinson's disease admissions were identified during the study period.

### **Coding errors**

The coding error rate was calculated using data from the three sources: 1,811 admissions from SUS database, 188 from PICS database only, and 479 admissions from the hospital number supplementary search (Table 2). In total, 667 of 2,478 admissions were not coded as having Parkinson's disease on discharge from hospital, and were therefore not identified from the SUS database search, during the study period. This gives a coding error rate of 27%.

### **Non-elective admissions**

1,412 (57%) of the admissions were non-elective (Table 1). These were accounted for by 747 patients: median age 79 years (interquartile range 71-85) and 57% were male. 60% (n=451 patients) were admitted only once during the study period and 40% had repeat hospital admissions (range 2-18 admissions). Median length of hospital stay was 6 days (interquartile range 1-18). 45% of the non-elective admissions were recorded under the general medical team, 21% geriatric medicine, 7% general surgery, 5% trauma and orthopaedics, 5% accident and emergency, 4% neurosurgery, and only 1% were admitted to the neurology team. Infections (20%), and falls, fractures and injuries (15%) were the commonest reason for non-elective admission (Table 3).

### **Discussion**

This study showed a significant under-coding of Parkinson's disease on discharge from hospital. Eight percent (188/2,478) of all admissions were identified by the PICS database only, implying that, although Parkinson's disease medications were prescribed during



hospitalisation, Parkinson's disease diagnosis was not coded on discharge, so these admissions were not found in our SUS database search. Another 19% of admissions were identified by searching both databases, using the hospital numbers of patients identified from our initial search of the SUS and PICS databases, suggesting further under-estimation of Parkinson's disease admissions by SUS. Therefore, overall we found that 27% of Parkinson's disease admissions were not recorded as such on the SUS database during the study period.

The high under-reporting of Parkinson's disease admissions shown in our study questions the usefulness of SUS data for Parkinson's disease healthcare planning. The financial implications of such errors on individual hospital trusts are likely to be substantial as previously shown. [11, 12] Given that the annual cost of Parkinson's disease hospitalisation in England was estimated to be £227 annually by Low *et al*, [3] if the under-reporting of admissions shown in our study is repeated nationally, the NHS expenditure on Parkinson's disease admissions in England is under-estimated by approximately £61 million annually.

Under-coding of other chronic conditions has also been reported when hospital inpatient data were used.[13] Anwar *et al*. reported 41% under-coding of diabetes admissions, when Scottish inpatient hospital data were compared with the Scottish National Diabetes register.[5] In another study, an estimated 9% of diabetes hospital admissions were not coded when HES data were compared with data from the English National Diabetes audit.[13] An audit of NHS trusts in England (2012/13) conducted by the Audit Commission reported a mean coding error rate of 11% for all primary diagnoses and 15% for secondary diagnoses for inpatient spells.[14] These data suggest that the problem of accurate coding of chronic diseases is widespread across many disease areas, meaning chronic conditions are being under-represented by current NHS planning models, and therefore disadvantaged in their access to resources.

Compared with previous work, our study showed a much higher coding error rate. Several reasons may account for the difference in coding error rates. Firstly, our study was disease-specific, whereas the NHS audit reported an overall coding error rate for several hospitals and all diagnoses. Secondly, coding accuracy for Parkinson's disease is likely to vary across different hospitals, as occurs with other chronic conditions. [5, 13] The majority of admissions in our study (57%) were non-elective, and infections, falls, fractures, and injuries were the commonest primary reasons for these admissions. Since Parkinson's disease was a secondary diagnosis during these admissions, the diagnosis was possibly less likely to be recorded on discharge. Lastly, in our study, the majority of non-elective admissions were recorded under teams other than neurological or geriatric teams, which may account for the high Parkinson's disease under-coding.

The NHS audit in 2012/13 found that coding inaccuracies for inpatient spells were mainly due to poor recording of secondary diagnosis codes by coders, [14] who are not medically trained. In addition, discharge summaries which contained inadequate and inaccurate information were often used to obtain information for coding. [14] In other studies, lack of involvement and awareness of the importance of coding by medical staff were some of the key factors contributing to coding errors. [12, 15] Given the reliance of NHS planning and resource use on these data, quality systems and training need to be implemented to ensure the data are fit for purpose.

Improving medical documentation and involvement of clinicians in the coding process has been reported to improve coding accuracy, [15, 16] but the evidence base for these interventions is limited. Other studies have evaluated the impact of medical staff training on accurate and appropriate documentation and produced conflicting results. [17-19] Standardising medical records may potentially improve coding accuracy as shown in an audit

conducted by the Royal College of Physicians in the UK. [20] Multicentre studies are required to test the impact of such interventions on coding accuracy.

We have proposed recommendations which are aimed at tackling these potential sources of coding errors. These include dissemination of information regarding importance of accurate and legible handwritten inpatient medical documentation on all wards, and further training of coders. Coding of neurological diagnoses for patients who attend the neurology outpatients department has also been proposed. Senior clinicians who review patients in these clinics are more likely to record accurate neurological diagnoses. Inpatient medical records in our hospital are handwritten, however, outpatient records are electronic, and these are linked to the inpatient prescribing database which is also available to coders for use during coding. Accurate outpatient coding may improve inpatient coding of neurological diagnoses. We plan to assess the effect of this intervention on inpatient coding of neurological diagnoses in the future. If results show an improvement in the coding error rate, this intervention will be trialled in other departments.

Limitations of our study include its reliance on retrospective data which may lead to inclusion of admissions for patients without Parkinson's disease. We addressed this potential problem by reviewing patient records identified from the PICS database who had prescriptions for Parkinson's disease medication, patients aged under 40years, and excluded those without Parkinson's disease. Admissions identified from the SUS database only, but having no Parkinson's disease medications prescription may reflect patients with early disease who are drug naïve. In addition this may represent prescription errors which are common when Parkinson's disease patients are hospitalised. [21] It is also plausible that a proportion of these could have been incorrectly coded as having Parkinson's disease. Due to time constraints and the large numbers of admissions obtained from the SUS database we could not verify the accuracy of diagnosis for all included patients. The capture-recapture analysis

underestimated the number of admissions missed by SUS and PICS databases suggesting that it is a way of approximating missed admissions.

Given that life expectancy and thus Parkinson's disease prevalence is expected to rise in the coming decades, the NHS needs to take urgent action to implement measures aimed at improving coding accuracy and therefore healthcare planning and hospital reimbursement.

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All authors approved the final manuscript for submission.

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