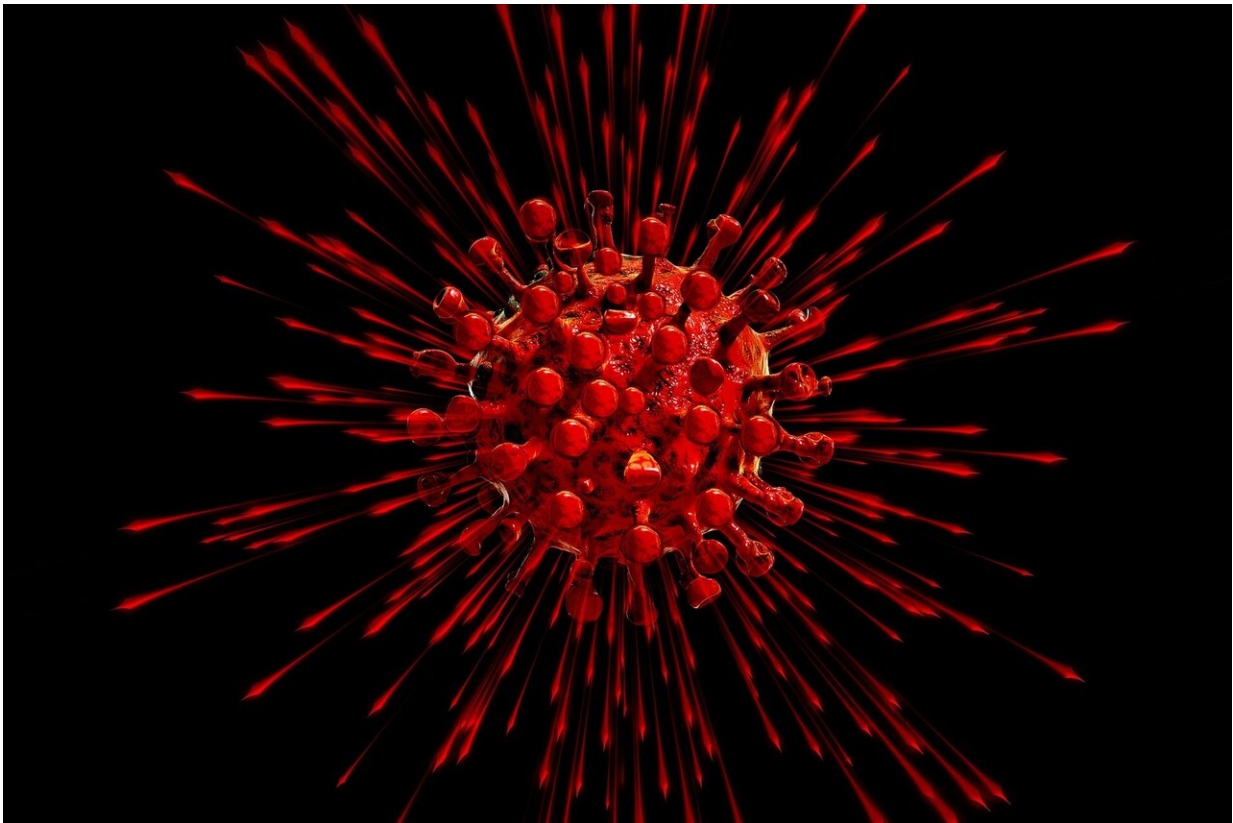


# Long COVID cases under-reported in NHS GP records

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Using the full pseudonymised GP records of 57.9 million patients in England, researchers at Oxford University and the London School of Hygiene and Tropical Medicine have found that formally recorded

diagnoses of long COVID are substantially lower than previous survey estimates for the same condition. This finding raises important questions about how long COVID is diagnosed, recorded, and managed in the NHS.

Numerous recent studies have used questionnaire research methods to determine the prevalence of long COVID, with the most recent estimates suggesting that approximately 2 million people have the condition (REACT2) and that between 7.8% and 17% of COVID patients experience symptoms for more than 12 weeks (National Core Studies Programme).

By contrast, for a study published today in the *British Journal of General Practice*, the research team ran an analysis across the full electronic health records of 57.9 million patients in England, in order to identify all those with a diagnostic code for long COVID entered by their GP. They found only 23,273 cases ever formally recorded between February 2020 and April 2021, in a sample covering 96% of the population. Cases ranged from 20.3 per 100,000 people in the East of England, to 55.6 per 100,000 in London, with 52.1 cases per 100,000 women compared with 28.1 cases per 100,000 men. Interestingly, levels of reporting also varied greatly between GP practices, and with the type of computer-based systems used by GPs to record patient information.

The researchers speculate in the paper that this significant discrepancy between [survey data](#) and patient records may be attributable to a range of possible factors including: patients not yet presenting to [primary care](#) with long COVID; different clinicians and patients holding different diagnostic thresholds or criteria for using the diagnosis; and issues around how the diagnosis is being recorded in computer systems.

Lead researcher Dr. Ben Goldacre from the University of Oxford's Nuffield Department of Primary Care Health Sciences, said: "We were

very surprised to see almost a hundred-fold difference in prevalence between population survey estimates and formally recorded diagnoses for the same condition. Good data on long COVID will be crucial for research into the prevalence of long COVID, its causes and consequences, and to plan services effectively.

"Since initially publishing a pre-print of this research in May, we have taken our findings to the National Institute for Health and Care Excellence (NICE), NHS England, and GP software systems designers and have had extensive conversations about how to address the issues highlighted by this research."

Long COVID is an emerging condition that has been broadly defined as a continuation of the symptoms of COVID-19 for more than four weeks. Reported symptoms vary, but commonly include breathlessness, headaches, cough, fatigue, and cognitive impairment or 'brain fog.' Beyond this, relatively little is known about the condition, with doctors and researchers working quickly to better understand it. As a result of this uncertainty, it has been challenging to issue clinical guidelines, create and communicate new diagnostic codes for use in GP computer systems, and communicate the current evidence relating to the condition to doctors.

This is the first study to be published in a journal using the expanded OpenSAFELY platform, which is now running analyses securely across the full electronic health records of 57.9 million patients, 96% of the English population. OpenSAFELY is a new and highly secure data analysis software platform created by Oxford researchers working on behalf of NHS England during the COVID-19 pandemic. It was built specifically to address privacy concerns around access to patient records for research. OpenSAFELY is the first service ever to run research analyses across the full GP records of almost the whole population.

**More information:** Alex J Walker et al, Clinical coding of long COVID in English primary care: a federated analysis of 58 million patient records in situ using OpenSAFELY, *British Journal of General Practice* (2021). [DOI: 10.3399/BJGP.2021.0301](https://doi.org/10.3399/BJGP.2021.0301)

Provided by University of Oxford

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