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RESPIRATORY MEDICINE

"Silent scandal" of missing lung diagnostics in England's most deprived areas—where respiratory disease is most prevalent

Lung conditions are the third biggest killer in the UK, yet *The BMJ* finds a postcode lottery for access to crucial diagnostic services that most impacts the areas with the highest burden. **Sally Howard** reports

Sally Howard *freelance journalist*

The BMJ has found that patients in some of the most deprived areas of the UK, where respiratory conditions including chronic obstructive pulmonary disease (COPD) and asthma are twice as prevalent,[1] have limited or no access to crucial respiratory diagnostics.

GPs in some of the worst affected areas say the fact they have no means of referring patients for tests, including spirometry and fractional exhaled nitric oxide (FeNO) analysis, is "troubling" and "a silent scandal"—despite NHS England trumpeting its rollout of "one stop shop" community diagnostic centres (CDCs),[2] some of which will be run by private providers.[3]

London GP (and BMJ columnist) Rammya Mathew says COPD is a "known disease of deprivation and a key focus of Core20PLUS5"—the NHS England initiative launched in 2021 to reduce healthcare inequalities at both national and system level.

In response to *The BMJ*'s findings, Sarah MacFadyen, head of policy and external affairs at charity Asthma + Lung UK, says, "It's concerning that spirometry provision is so patchy across England and that so many people with COPD are missing out on this vital test to confirm their diagnosis. While some areas are finding innovative ways to provide testing, many integrated care boards (ICBs) are not commissioning spirometry, and others have no record of how or if tests are being provided."

John Hurst, professor of respiratory medicine at UCL, tells *The BMJ* that inequity in access to spirometry is a "national scandal."

Fifth biggest killer—yet patchy or unclear provision

Nearly 30 000 people die from COPD each year in the UK, making it the second greatest cause of death from lung disease after lung cancer and the UK's fifth biggest killer. According to NHS England, "The annual economic burden of asthma and COPD on the NHS in the UK is estimated as £3bn and £1.9bn respectively. Both underdiagnosis and overdiagnosis of respiratory conditions leads to delayed treatment and increased chance of acute admissions."[4]

The government's major conditions strategy[5] highlights the need for early and accurate diagnoses for people with lung conditions and one of the aims of Core20PLUS5 is to "narrow health inequalities" in chronic respiratory disease.[6] A 2019 NICE guideline update states that spirometry should be performed for diagnosis of COPD and asthma[7] and FeNO testing for a diagnosis of asthma.[8]

Spirometry, a lung function test that measures how much air a patient can breathe out in one forced breath, is used to diagnose COPD and asthma. Spirometry tests were suspended during the pandemic because of concerns about infection risk (which have now been resolved). Asthma + Lung UK said this resulted in a 51% drop in COPD diagnoses in 2022. FeNO testing is a new diagnostic that measures levels of nitric oxide in a patient's breath—high levels indicate the inflammation often seen in cases of asthma.

The BMJ requested information on access to spirometry through press offices and freedom of information requests from England's 42 ICBs. We also looked at information the boards had put in the public domain around access to spirometry from general practice, and corroborated some ICBs' depiction of availability of diagnostics in their regions by speaking with local GPs. Seventeen ICBs did not respond to *The BMJ*'s three requests for information.

Of the ICBs that did respond, *The BMJ* found that provision was patchy and the full picture unclear in West Yorkshire (West Yorkshire ICB), and that spirometry was no longer commissioned in Hampshire and the Isle of Wight. Hampshire and the Isle of Wight ICB said there was "no money" available to set up diagnostic hubs at primary care network (PCN) level, as some ICBs have done.

Humber and North Yorkshire ICB told *The BMJ* that it "did not commission spirometry as a local enhanced service" (LES) and did not have a clear picture of provision in its region. Derby and Derbyshire ICB could not give a picture of availability in its area; however, a Derbyshire based GP told *The BMJ* that she has no access to services to which to refer her patients.

Spirometry is not available for some patients in Devon (One Devon ICB). Katie Musgrave is a GP in Paignton who has been told that spirometry is not available for her patients in her NHS trust and that she has to diagnose COPD on a clinical basis.

Musgrave believes that without access to diagnostics "many GPs will tend not to make the diagnosis or begin treatment." In Musgrave's view, breathless

patients not being adequately managed, or not being formally diagnosed, risks them developing "severe symptoms and exacerbations that contribute to morbidity and mortality." She is seeing exacerbations for breathless patients in her practice.

Deprivation, lack of access, emergency admissions, deaths

In Cornwall, a region with high levels of deprivation and long waiting lists for lung condition diagnosis, the ICB does not commission spirometry and cannot give a clear picture of provision, although it says there is some coverage by CDCs. It adds that it is "considering options for commissioning spirometry in primary care and developing an integrated respiratory pathway with a recommendation for spirometry to be carried out in primary care."

According to Office for National Statistics 2021 census data, 53.9% of households in Cornwall had at least one of the four measures of deprivation (unemployment, low educational attainment, poor household health, and overcrowded housing).[9]

Bob Hodges, 80, runs COPD patient peer support group Breathe Club Falmouth in Cornwall, which often receives patient referrals from secondary care (after six week NHS rehab ceases). Hodges has COPD after asbestos exposure during his career as a ship repair engineer—"occupational COPD is common down here"—and says that slow diagnosis can weigh heavily on patients. "Often they will see their GP for long term breathlessness and maybe get an inhaler but they don't know what they've got, nor why," Hodges says. "I do understand that GPs are stretched, though."

Of the ICBs that didn't respond to *The BMJ*'s request for information, the picture is bleak in Rotherham and Doncaster (South Yorkshire ICB), two regions with historically high levels of diagnosis of COPD because of large communities of former miners. Doncaster GP Dean Eggitt says that GPs in his PCN have no access to spirometry following the closure of services during covid. "We refer to secondary care and they send letters back saying, 'It's not our problem,'" he says.

In several cases screening trucks, part of an NHS lung cancer screening programme initiative,[10] pick up a patient's likely COPD and refer to Eggitt or other GPs in his PCN for diagnostic tests. "But there's nothing we can do as access to spirometry is nil," he says.

The 2021 ONS data show 34.7% of Doncaster's residents are deprived in at least one measure,[11] with the city ranking in the bottom 20% of local authority areas in England for health in 2021.[12] NHS England's own data rank Doncaster in deprivation quintile 1,[13] in a one to five ranking based on the English indices of deprivation 2019.[14,15]

Asthma + Lung UK tells *The BMJ* that many of the areas with the highest rates of emergency admissions and deaths from lung conditions are areas with higher levels of deprivation. Chief executive Sarah Woolnough says, "It's clear that far too many people, especially those in poverty, are missing out on timely diagnosis and support because the provision of lung function diagnostic tests is currently not good enough."

Increased requirements for testing

In England, spirometry has historically been delivered in general practices in primary care. Guidelines introduced from 2019, however, require staff using spirometry kits to be certificated by the Association for Respiratory Technology and Physiology (ARTP) in interpreting spirometry results and registered on the National Spirometry Register.[16] This means that many practices that formerly offered this diagnostic now face high barriers to continue to offer it because they lack the funds and workforce capacity needed for training and registration.

While there is funding for CDCs and GPs are now able to refer to these hubs[17] (see box 1), there is no ringfenced funding for spirometry in the NHS. With diagnostic backlogs building since the pandemic's cessation of services, and patchy resumption of provision, GPs have been sounding the alarm about the spirometry crisis for months.[18,19] A national picture has been absent, however, and there are no central data available on spirometry provision. *The BMJ*'s inquiries are an attempt to build a picture of current provision across England's IBCs. Similar problems around the patchy resumption of spirometry in general practice are evident in Scotland[20] and Wales.[21]

Another BMJ finding was disparities of access to diagnostic services between more and less deprived areas within ICBs, including in London. NHS North West London ICB told *The BMJ* that spirometry was included as a LES through respiratory diagnostic hubs, nine of which are currently operational. Aparna Pal is a GP in Ealing, an area within the ICB which is home to a large South Asian community with historically high rates of COPD diagnosis. She says, however, that her area is not adequately serviced by the hubs, which are too far away for patients in her area to travel to and overstretched by referrals from practices nearby.

Mathew, a GP in Brent who is campaigning for awareness of the spirometry provision crisis in primary care, is also within the North West London ICB. She says she had no access to spirometry for her patients for "several months," even for patients who have been admitted to hospital with suspected COPD.

In West Yorkshire, a region with variable provision, some at-risk patients are being reached with a pilot spirometry bus service targeting those with COPD symptoms. The service is run by private provider Innovate Healthcare.[22]

There are deadly consequences of this postcode lottery for respiratory diagnostics. In an August report, *Diagnosing the problem: Right test, right time*,[23] Asthma + Lung UK signalled concern about the knock-on effects of delayed diagnosis and access to care.

Without timely and accurate diagnosis, the report said, people with lung conditions do not get treatment for their symptoms, suffer acute and long term deterioration, and die early. In a patient survey that supported the report, 18.4% of respondents with COPD reported receiving best practice care in primary care according to the "five fundamentals" of COPD care outlined by NICE.[24] Some 30% of patients with asthma reported that they had received best practice in care, defined as "an annual asthma review, inhaler technique check, and written action plan."

Of those diagnosed with a lung condition in the two years to 2023 in Asthma + Lung UK's patient study, 36.8% had waited for more than six months for a diagnosis. Some 18.2% of respondents said lack of availability of diagnostic tests was responsible for a lack of diagnosis.

The charity has produced a report on the impact of GPs having to diagnose lung conditions without diagnostics, published on 26 September.

Funding the way forward

Asthma + Lung UK tells *The BMJ* that the lack of clear data around spirometry gaps, "needs to be tackled urgently by ICBs" so they can plan services and make sure workforces are adequately trained for current and future demand. Crucial in the charity's view is for NHS England to provide funding for quality assured spirometry at a

primary care level, incentivising spirometry as a paid-for diagnostic test within the GP contract.

The charity's report points out that with spirometry not commissioned, ICBs currently have to create a business case for including the test, a process Woolnough describes as "slow and cumbersome." NHS England's hope that PCNs will get spirometry off the ground in the face of workforce problems and with no funding for equipment, training, or registration is, Mathew points out, "a big ask, especially in more deprived areas and where infrastructure and strong leadership are lacking."

Mathew is crossing her fingers that a new CDC at Willesden in north west London, in the process of being built, will accept referrals from her practice when it opens. She worries for the nation's many undiagnosed as well as the stress on overstretched GPs. "In many parts of the country, spirometry access is sparse or even non-existent," she says. "This has been the case for at least three years now and it's high time this was prioritised by the government and NHS England."

In Doncaster, GP Eggitt has negotiated off-label diagnostics for the patients who are most at risk of COPD, using staff who are not ARTP trained, which he says is "a sticking plaster tactic" in the face of an emergency. "What we need, rather than screening programmes that pile more work on GPs' plates, is to commission spirometry, which is needed here and now for patients who will die of heart failure as their lungs are rotting."

Box 1: Will diagnostic hubs help?

In response to *The BMJ*'s questions about how it plans to tackle regional gaps in access to respiratory diagnostics, NHS England said, "We are working to support restoration of spirometry to above pre-pandemic levels and expand access in community settings, including by offering spirometry in CDCs."

The creation of CDCs was recommended following Mike Richards' review of NHS diagnostics capacity in 2020.[25] On 3 August 2023 NHS England announced that these centres would be directly accessible to GPs without requiring a specialist referral.[26] CDCs, up to 160 of which have been promised, were intended to add capacity, however, not replace it from primary care, with these centres unable to meet diagnostic demand in most areas.[23]

When it comes to spirometry, GP and Asthma + Lung UK clinical lead Andy Whittamore told *The BMJ* that repeat announcements around CDCs have given GP practices the false impression that "someone else was going to do it."

The BMA's GP Committee warned on 3 August that plans for GPs to be able to refer patients with symptoms of heart and respiratory problems directly to CDCs will pile administrative pressure on overstretched practices.[27]

Devon GP Katie Musgrave agrees that "every piece of work transferred to general practice is a concern in the current climate." She worries that the results from CDCs when GPs do manage to refer "would not be interpreted or have clinical advice added (as generally happens through NHS services)."

London GP (and BMJ columnist) Rammya Mathew labelled NHS England's focus on CDCs a "political soundbite." She said, "It's very vague what the centres will offer in terms of tackling the spirometry crisis, and the diagnostic provision will be limited and inconvenient for lots of patients who will have to travel far for these tests."

Best practice: the areas with good respiratory diagnostic availability

The ICBs with the best coverage of spirometry services for GPs to refer to include NHS Surrey Heartlands ICB, a region in the least deprived deciles in the government's 2019 index of multiple deprivation. The ICB told *The BMJ* that spirometry was currently provided in 73% of their GP practices and that the ICB would guarantee "100% coverage" for its population through other services, including, for example, through a breathlessness service pilot.

Nottingham and Nottinghamshire ICB (mid-ranking in the index of multiple deprivation) said its spirometry offer was underpinned by agreement with an enhanced service delivery specification, with some general practices having a service level agreement in place for spirometry to be delivered by private community health services provider Nottingham Citycare on their behalf. The ICB is home to a project run by private health and social care service contractor Primary Integrated Community Services, which offers spirometry testing in GP practices across mid-Nottinghamshire delivered by an ARTP accredited nurse.[28]

Spirometry is also commissioned as an LES in Shropshire, Telford, and Wrekin, with 86% of general practices offering the service. Buckinghamshire, Oxfordshire, and Berkshire West ICB has a spirometry supplementary network service,[29] an LES for PCNs to offer diagnostic spirometry: 37 out of 50 PCNs in the board were signed up to this service as of August 2023.

At Open Door Surgery, a small practice focused on management of long term conditions in Balham in Southwest London ICB, spirometry testing is led by an ARTP accredited respiratory nurse supported by a healthcare assistant at a designated Saturday morning spirometry clinic, which also offers FeNO testing. Sudesh Mittal, a senior GP at the practice, along with a respiratory doctor from nearby St George's Hospital, discuss complex cases with the nurse when needed. Funding for the clinic is piecemeal, with some LES funding because of extended hours and some for each spirometry test as an LES from the ICB. A FeNO machine was bought for the practice by the PCN a few years ago.

"On the plus side the practice has immediate access to respiratory diagnostics," Mittal tells *The BMJ*. "It's also good to have the expertise of a respiratory nurse on staff." The downside, he says, is the lack of proper funding to provide the service, especially the lack of funding to maintain spirometry and FeNO devices. "I can see why many practices can't afford to offer the spirometry at practice level," he says.

Waiting, wheezing: patient case studies

I was diagnosed after being admitted to hospital with worsening symptoms, while waiting for referral

Mr O, 56, from south Yorkshire, says, "I'd been coughing up phlegm for a few years and didn't think much of it as I'd been a smoker for 28 years and I always had chest infections on and off: also it would come for a few months at a time and then go.

"Then I started not being able to catch my breath when I climbed the stairs to bed. I work as a taxi driver and it got so I'd come home from work and didn't want to do anything. I was so tired out. I went to my doctor about it but it was covid then [2021] and they said they weren't doing any tests and that they would refer me to the hospital.

"It was when I was waiting for this appointment that the breathlessness got so bad that I went into hospital and they put me on oxygen. That's where they diagnosed my COPD. Being on the Facebook COPD support group I feel lucky in a way as I know there are others like me that are just stuck on waiting lists. I have a long acting inhaler now and my symptoms are a bit better."

I wasn't told about my diagnosis for two years—until a chance conversation

Eddie, 63, from Telford, Shropshire, discovered he had COPD by accident. He collapsed in 2014 with heart palpitations and was diagnosed with severe sleep apnoea and a heart condition. Nobody mentioned COPD although it was documented, unbeknown to him, on his medical records.

He says, "Nearly two years later I found out that I had COPD by chance. I was waiting for some arm surgery in private care when my GP reviewed my records and told me that I had to inform my surgeon and anaesthetist that I had COPD because this put me at risk. This was news to me. It turned out that the hospital had diagnosed me nearly two years before. In that time I wasn't told how to manage my COPD, given any medication, or referred for treatment.

"It's upsetting knowing that there are thousands of people who could be in the dark about their COPD diagnosis. I know how lonely that can be. Not knowing that I had a serious lung condition and battling daily and through the night with breathlessness was physically and mentally exhausting. From the moment I woke up, it's all I could think about. Everyday tasks such as putting my socks on, walking up the stairs, and bringing the shopping in from the car felt near impossible."

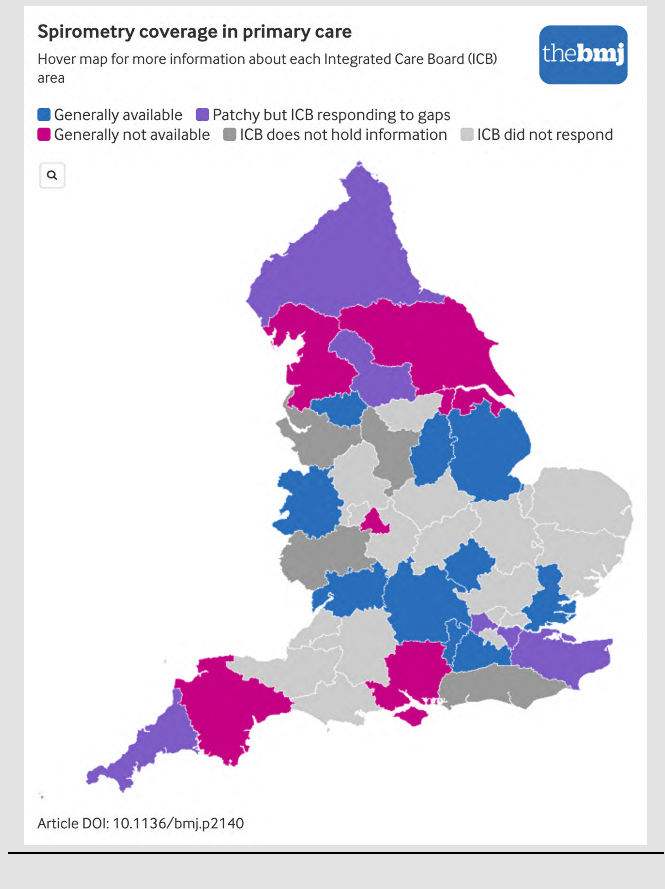
Eddie retired on medical grounds from his job as a chief technologist in IT in July 2020.

"The treatment I've received for COPD has not been very good and I can't remember the last time I had a review, but it was probably before the pandemic. I last had a spirometry test in February 2020 which isn't good enough. I have no idea how well my lungs are functioning. My surgery has not offered spirometry since the beginning of 2020.

"It worries me that my COPD is not being monitored in any way, as it's impossible to get a spirometry test anywhere near me. I have lost 17 kgs in the past year to try and ease my breathing and last year I was given a 12 week course of pulmonary rehab through an app called My Health. At the moment, for COPD I take a reliever Salbutamol inhaler, a preventer inhaler, and a dual inhaler."

What *The BMJ* found

The BMJ requested information on access to spirometry through press offices and freedom of information requests from England's 42 integrated care boards. We also looked at information the boards had put into the public domain around access to spirometry from general practice and corroborated some ICBs' depiction of availability of diagnostics in their regions by speaking with local GPs.



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