

# Chair's Perspective

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## Early and accurate respiratory diagnosis: a patient safety issue needing more serious attention

Many respiratory interested healthcare professionals have expressed to me with frustration that the application of rigour and quality control for a diagnosis of diabetes mellitus or hypertension is not replicated as uniformly for respiratory symptoms or long-term respiratory disease. These conversations inevitably lead to why that is and then stories of the consequences.

Misdiagnosis as a patient safety issue has come to the fore in recent years in the mainstream journals. Two perspectives in the *New England Journal of Medicine* in 2015 reflect on the costs of misdiagnosis, the need for a root cause analysis when it occurs in order to improve systems and looks further, suggesting incentivising reductions in misdiagnosis rates.<sup>1,2</sup> One of the papers commented:

*'With health care costing more than ever before, and missed or delayed diagnoses often resulting in higher downstream costs for treating more advanced disease, the financial implications of misdiagnosis can be substantial' – 10 per cent of diagnoses are incorrect.'*

In respiratory medicine in recent years we have been hearing about not enough, too much and poor quality around asthma and COPD diagnosis. This suggests that respiratory diagnosis isn't always easy, maybe doesn't have the highest priority and therefore resources, and that we haven't yet adequately described or disseminated a structured approach towards assessing respiratory symptoms. Has our last decade of incentivisation taken us further down the road of misdiagnosis through linking income essential to primary care with prevalence on single disease registers and before being sure that the evidence can be implemented?

I remember in 2001 as a GP registrar my trainer walking into my room saying a new bit of kit had been delivered by the Primary Care Trust and did I want to try and work out how to use it? It was the first time I'd seen a spirometer and I had no idea what it was for – I confess it lay on the shelf and I never opened the box – I had other priorities in that year. Two years later I was a GP partner building a COPD and asthma register learning on the job, fast – I had to prove my added value! I spent subsequent years reviewing the quality and reflecting on the impact. Others will have done the same, and will be doing it still, but hopefully everyone has now recognised the need.



In October last year the respiratory community received a wake-up call about the need for accurate diagnosis with the publication of the COPD national audit.<sup>3</sup> This report revealed that, for 48,000 patients whose data were extracted from 62% of general practices in Wales, at best only about 50% of the population had evidence of a correct diagnosis of COPD and at worst the figure was as low as 15%.

The audit report was closely followed by a paper in the *Journal of the American Medical Association (JAMA)* in January 2017 reporting a prospective, multicentre cohort study that was conducted in 10 Canadian cities from January 2012 to February 2016 looking at whether asthma medication can be safely stopped in people with no current evidence of asthma.<sup>4</sup> The results suggested that, after review, 203 of the 613 randomly selected cohort diagnosed with asthma in the last 5 years did not have asthma.

These recent reports and research papers reinforce the current PCRS-UK campaign to raise awareness among healthcare professionals of the importance of diagnosing respiratory conditions early and accurately and of getting the basics right because diagnosis is a basic building block of quality care. Our campaign is working to change the culture and approach of healthcare professionals and to improve skills and competencies in making a diagnosis.

### The problems that need to be addressed

#### *Over or inappropriate use of treatment*

In the early to mid-2000s there was a surge of optimism about the benefits of pharmacological treatment for people with COPD with the use of combination inhaled corticosteroid (ICS) long-acting beta agonist (LABA) and long-acting muscarinic antagonist (LAMA) inhalers. The previous nihilism around COPD therapy options led the respiratory community to hope that this would be the equivalent of statins for secondary prevention of heart disease. The unintended consequence was the widespread use of ICS in people who didn't fill the criteria for treatment and this led to unnecessary cost to the NHS through use of what were, at that time, inhalers that cost £30–60 per month. It also caused possible harm to patients including minor steroid side effects, pneumonia and, in theory, adrenal suppression which could put people at risk of a withdrawal-related adrenal crisis. Towards the latter part of that decade we then began to realise that we had problems with accurate

diagnosis and that we were sometimes assuming people had COPD without being absolutely sure about it.

#### In your practice do you know:

- What proportion of people on the COPD register has a spirometric result, CT chest or gas diffusion test that confirms the diagnosis of COPD?
- What proportion of people with asthma on your register have a clear statement in the notes when the diagnosis was made that justifies starting what is essentially lifelong therapy?

Go to <https://goo.gl/LX47gX> to download the quality improvement slide kit following the primary care COPD audit by the Royal College of Physicians

#### *Case study: cough*

In the cough diagnosis case in our case studies article in this issue (see page 12), the diagnostician works with the woman in question to manage her expectations and share an approach towards finding the cause. Chronic cough can have many options, needs initial investigations and trials of therapy and it takes time. Opting for therapy before being clear on cause may result in therapy that doesn't work and disengagement.

#### *Feedback: COPD or bronchiectasis?*

A diagnostic difficulty, which we all face, is the patient with risks, symptoms and spirometry suggesting COPD but who may in fact have bronchiectasis. If this is the case, the treatments, patient education and supported self-management will be quite different. We don't present any easy answers to this, though the new GOLD guideline approach to assessing COPD for therapy does encourage us to focus on asking and recording exacerbations, so recognising those with higher numbers of flare-ups might help focus our thoughts on whether bronchiectasis is possible.<sup>5</sup> Each time

people with bronchiectasis get another infection their lungs decline, so timely consideration is required. Our interview with Barbara Preston (see page 23), a member of the PCRS-UK Lay Reference Group, who had bronchiectasis as a child but was not diagnosed until she was an adult, illustrates how this delay to diagnosis impacts on the patient.

#### *Incomplete diagnosis*

The annual focus on the single disease Quality and Outcomes Framework (QOF) review such as COPD and heart failure also has consequences for missing other causes of respiratory symptoms such as breathlessness. We know that, by the time people have daily disabling breathlessness, it is likely they will have multimorbidity and people with COPD are at much higher risk of lung cancer which may present as a change in cough or breathlessness. Therefore, unless we develop systems to ensure we seek to obtain or exclude all of the diagnoses that might be causing a patient's chronic respiratory symptoms, we may leave people without the right care plan.

In another of the diagnosis cases in this edition (See page 14) an older male patient is assumed to have COPD quite reasonably, but it is only a year or two later through questioning the diagnosis at his 'flare-up' and in part due to continuity of care that his other diagnosis is revealed.

#### **A new approach**

Breathlessness is a very common problem – 10% of adults and 30% of older adults have been breathless every day for the last 3 months or longer. However, we do not seem to be recording this problem at these rates in our surgeries, outpatients and wards when studies have looked at presentation to health professionals. It is easy for patients to adapt to breathlessness and, indeed, to pass it off as not being a problem until it's late in its progression.

*Do we routinely ask people about their breathlessness or offer them a test? It's not in any health check and what test could we do anyway?*

So we need to be thinking about how we pick up people who are breathless much earlier. Ideally we need a policy from 'the centre' that looks at proactive breathlessness assessment as a value-based prevention strategy – whether it is a question about an aspect of someone's breathlessness, a fitness test or on-line breathlessness quiz. We have already had two very successful national media campaigns which ran last summer – the Public Health England Be Clear on Cancer Campaign, which raised awareness of the symptoms of breathlessness, and the British Lung Foundation Listen to your Lungs Campaign, which encouraged people to ask healthcare professionals about their breathlessness and do an online breathlessness assessment test (See <https://breathtest.blf.org.uk/>). Over 200,000 people have used this test since it was launched. This focus at national level is very welcome in encouraging people to think about breathlessness.

Would it now make sense as we start to re-design QOF and our wider incentive system – a process that has already started in Scotland – to reward quality of diagnosis and not just the diagnosis itself? Of course we will need a diagnostic guideline everyone can agree with and an agreed stepped assessment process for respiratory symptoms such as cough and breathlessness where each step

is manageable for both patient and diagnostician and at the end a diagnosis everyone can believe.

### Take home message

The important message that clinicians need to take on board when diagnosing respiratory disease is that they need to be clear about what it is they need to do to achieve an early and accurate diagnosis and that they are trained to carry out that role.

If clinicians feel confident about the diagnosis they have made, it follows that patients will feel more reassured about their diagnosis because they will understand it and know how it has been arrived at. This will encourage them to adhere to the therapy or treatment they have been prescribed. Only then will we be able to feel confident that our patients are receiving optimal care.

### Diagnosis – the basic building block of good respiratory care

- Respiratory diagnosis is a complex process and needs to be taken seriously by the whole team. It requires:
  - a structured systematic approach: a person activated to ask for help, a responsive system and a diagnostician who has a clear path to follow that everyone understands, referral for objective tests by someone trained to do them and a cycle of regular review (this will not be achieved within a one-off single 10 minute consultation);
  - objective evidence from tests, clinical judgement and shared decision making.
- Think symptoms (e.g. cough, breathlessness) and explore these with an open mind. Avoid pre-determined diagnoses for asthma/COPD (e.g. it is too easy to think that a smoker with cough or breathlessness has COPD or that a young child with cough or wheeze always has asthma).
- Existing respiratory diagnoses need to be validated/confirmed and not taken for granted.

*This edition sees an editorial change; we say goodbye to Hilary Pinnock and welcome Iain Small as Editor. Hilary has successfully developed Primary Care Respiratory Update to become a popular update for grassroots members. Her strong academic credentials and eye for detail has ensured that its content informs and is highly respected. We look forward to Iain, already a member of the editorial team, who will contribute his own inspirational brand of challenge and humour.*

### Reference

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