PCRS Position Statement

Chronic Breathlessness: Ensuring quality diagnosis for everyone

September 2023

PCRS recognises a need for improvement in the timely diagnosis of people living with chronic breathlessness and generally welcomes the NHS England diagnostic pathway support tool. PCRS has some concerns that a diagnostic algorithm can communicate an oversimplification of diagnosis. We are disappointed that this pathway will not be accompanied by the long awaited and hoped for, but now deprioritised, NICE Breathlessness guideline. PCRS would highlight to those responsible for resourcing cardiorespiratory diagnostics that they should take care to avoid a disproportionate focus on 'hubs' to ensure that the comprehensive diagnostic approach seen in primary care is not eroded as a result.

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Background

In April 2023 NHS England published a diagnostic pathway support tool for the diagnosis of chronic adult breathlessness.[1] PCRS welcomes any measure that could improve timely and accurate diagnosis of chronic breathlessness for more people.

The increased focus on cardiorespiratory symptom diagnostics[2] comes at an important time for people who might be living with COPD but remain undiagnosed. The Taskforce for Lung Health[3] and a team from Imperial college in July 2023, published work that suggests there are approximately half a million people in England who remain undiagnosed.[4] The availability of quality spirometry and people adequately trained to perform and interpret is essential to any breathless diagnostic service. PCRS is concerned at the significant drop in people with spirometry confirmed COPD due to the pandemic and the slow pace of recovery in primary care.[5]

More than 2/3rds of chronic breathlessness has a cardiorespiratory origin and there will be multiple causes in about 1/3rd of people.[1] Primary care has a critical role and expertise in recognising and assessing undifferentiated symptoms such as breathlessness.

The new diagnostic process tool which in general PCRS welcomes, could help deliver a standardisation in approach and help ensure all causes of breathlessness in an individual are identified.

A diagnosis, of course, requires more than following an algorithm and ordering and receiving test results. Interpretation and communication of results requires quality training. Diagnosis must always include shared decisions about initial trials of treatment, paired with supportive self-care planning and importantly ensuring that people understand their diagnosis. We also note that some tests, for example, autoantibodies are missing but could provide earlier recognition and more direct referral for interstitial lung disease. Any questionnaire scores used within the algorithm need to be relevant and known to primary care and may also require specific training to deliver them so that the results are valid.

PCRS is aware that some diagnostic hub service provision includes investigation but not diagnosis. In this case it is crucial to ensure good communication back to primary care and ensure an adequately resourced and trained primary care to fill any gaps in hub provision.

PCRS would highlight to those responsible for resourcing cardiorespiratory diagnostics that they should take care to avoid a disproportionate focus on 'hubs' to ensure that the comprehensive diagnostic approach seen in primary care is not eroded as a result.

PCRS encourages commissioners to use the PCRS Fit to Care[6] work first published in 2017 and updated in 2022 that provides an excellent reference for service managers as well as helping healthcare professionals check that their learning matches their expected scope of practice.

PCRS recognises a risk of worsening health inequalities if local commissioners do not consider the needs of all groups. We would highlight here specifically but not exclusively that rural communities, and the homeless may be adversely affected if a hub only model is followed. There are also potential environmental impacts from increased travel for investigation that could otherwise be carried out locally. The use of point of care testing in primary care should be considered.

We were disappointed to hear in May 2023 that NICE has de-prioritised a new breathlessness guideline. Whilst we are confident that many in primary care will welcome the new diagnostic tool and use it because of the clear benefit to patients, we do not think there is sufficient support to ensure its comprehensive use. Any new tool or guidance inevitably needs additional resource and training and a NICE guideline is the mechanism by which recommendations become quality standards and then potentially quality improvement targets at practice or network level. Its absence means we currently lack a national approach to non-disease specific management whether medicinal or non-pharmacological such as psychological and behavioural therapies, mobility support, weight management and palliative care.

PCRS position

- PCRS welcomes in general the NHS England diagnostic pathway support tool for the diagnosis of chronic adult breathlessness.
- PCRS is concerned at the significant drop in people with spirometry confirmed COPD due to the pandemic and the slow pace of recovery in primary care.
- A diagnosis requires more than following an algorithm and ordering and receiving test results. Interpretation and communication of results requires quality training.

- PCRS is aware that some diagnostic hub service provision includes investigation but not diagnosis. In this case it is crucial to ensure good communication back to primary care and ensure an adequately resourced and trained primary care to fill any gaps in hub provision.
- PCRS would highlight to those responsible for resourcing cardiorespiratory diagnostics that they should take care to avoid a disproportionate focus on 'hubs', to ensure that the comprehensive diagnostic approach seen in primary care is not eroded as a result.
- PCRS encourages commissioners to use the PCRS Fit to Care work that provides an excellent reference for service managers as well as helping healthcare professionals check that their learning matches their expected scope of practice.
- PCRS recognises a risk of worsening health inequalities if local commissioners do not consider the needs of all groups, for example rural communities, and the homeless.
- PCRS was disappointed to hear in May 2023 that NICE has de-prioritised a new breathlessness guideline. Its absence means we currently lack a national approach to non-disease specific management whether medicinal or non-pharmacological such as psychological and behavioural therapies, mobility support and weight management

References

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