

Understanding the primary and secondary care burden of chronic cough, breathlessness and chronic breathlessness

Data insights from the CLEAR Respiratory Neighbourhood Extension Programme

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Background

Chronic cough, breathlessness and chronic breathlessness are common, undifferentiated respiratory symptoms placing significant demand on primary care. Estimated population prevalence of chronic cough reaches **4.9% at 12 months** (6.2% lifetime)¹, while we conservatively estimate that at least **9-11% of the general adult population** live with breathlessness of any duration and **25% of older adults**, based on NHSE's published estimate.² This is likely an underestimate as duration-defined estimates range internationally ~9-29% depending on definition and survey method. This also makes it difficult to define and truly understand the prevalence of 'chronic' breathlessness.

Despite this burden, systematic data on how these patients move through primary care pathways remains limited. The CLEAR programme sought to address this gap through analysis of real-world primary care data across four PCNs including 17 GP practices.

Methods

A sample dataset of 233,240 patient records from 17 practices from PCN networks (three in the North West and one in the East of England) was analysed, spanning January 2015 to December 2023. Approximately 11.5 million rows of data and 3,500 SNOMED codes were interrogated. Open-access sources including OHID public health profiles, BMA workforce data, and NHS England RTT waiting times data supplemented the analysis.

We first looked at patients coded with breathlessness, chronic dyspnea (breathlessness) and chronic cough. As very few patients were actually coded using the 'chronic dyspnea' code we expanded the search to look at patients presenting with 2 or more episodes shortness of breath at least 8 weeks apart - this is our proxy for the 'chronic breathlessness' cohort. Coded chronic cough was assessed among currently registered patients over the most recent five years; coded breathlessness over the full eight-year dataset (January 2015–December 2023).

233,240 patient records	11.5m rows of data	17 practices across 4 PCNs	3,500 SNOMED codes interrogated
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Results

Local coded prevalence, utilisation and pathway timing across the four PCNs

Under-coded prevalence

Local coded prevalence against published population estimates — likely significant underestimates.

Chronic cough

1%

4.9% est.

Breathlessness/Chronic Breathlessness

1.9%

6.8%

~ 9-11%

Of the 6.8% coded with breathlessness, only **28%** — **1.9%** of the total population, shown dark — are coded as **having 2 or more episodes 8 weeks or more apart (chronic)**. Coded figures are multi-year period rates; comparators are point-prevalence (breathlessness) and 12-month (cough) survey estimates. A complete multi-year coded rate would be expected to exceed a point prevalence, so the gap shown is conservative.

Higher primary care use

Patients with chronic cough or chronic breathlessness symptoms generated substantially higher primary care utilisation.

3×

more GP appointments per year than the general population — chronic breathlessness

2.8×

more GP appointments than the general population — chronic cough

Delayed referral

Median time from first presentation to referral, and the appointments accrued before it.

Chronic cough

17 months

over 29 appointments

Chronic breathlessness

21 months

over 45 appointments

Missed diagnostic opportunities and coding of 'red flag' symptoms

Investigations were infrequently performed for those with chronic symptoms and red flags rarely recorded.

Investigation	Ever done after symptom onset	Within 12 wks
CHRONIC BREATHLESSNESS		
CXR	53%	19.5%
ECG	33%	9%
BNP	8%	4%
CHRONIC COUGH		
CXR	45%	26.6%
Spirometry	9%	4.3%

Only 5.4%

of chronic cough patients were coded as having red flag symptoms and of those coded less than half were referred for two week wait of imaging.

Others had 2ww referrals but no red flag coded symptoms.

Unplanned care

Unplanned care utilisation was also markedly elevated in patients coded with chronic cough or chronic breathlessness over the study period.

2×

as likely to attend ED — chronic breathlessness vs general population

3–4×

as likely to need an unplanned admission

Unplanned admission rate over the study period for chronic breathlessness

47%

12% general population

Coded prevalence by age

Age Group	Breathlessness	Chronic breathlessness	Chronic cough
18-19	1.9%	0.3%	0.1%
20-29	2.6%	0.3%	0.4%
30-39	3.1%	0.4%	0.6%
40-49	3.7%	0.6%	0.7%
50-59	5.4%	1.2%	1.2%
60-69	8.2%	2.4%	1.6%
70-79	12.7%	4.3%	1.9%
80-89	16.8%	6.4%	1.5%
90+	14.1%	4.7%	0.5%

As observed in the coded dataset

The current primary care journey

First presentation

Undifferentiated cough or breathlessness presents in general practice; coding often does not capture it

Repeat attendance

2.7–3× the appointment rate of the general population, without a diagnosis being reached

Investigation often not performed consistently

Around half never received a chest X-ray.

Referral after 17–21 months

Following a median 29 (cough) or 45 (breathlessness) appointments

RUNNING IN PARALLEL Elevated unplanned care throughout — 2× ED attendance and 3–4× unplanned admission versus the general population.

Conclusions

These findings highlight substantial **missed diagnostic opportunities**, **delayed referral**, and **high system utilisation** for patients with chronic cough and chronic breathlessness. Structured neighbourhood-level approaches to pathway improvement — as piloted through CLEAR — offer a scalable model for earlier diagnosis and more efficient care.

LIMITATIONS

Key limitations included variability in SNOMED coding practice and the inability to track individual patient journeys.

SOURCES

1. McGarvey L, Morice AH, Martin A, *et al*. Burden of chronic cough in the UK: results from the 2018 National Health and Wellness Survey. *ERJ Open Res* 2023; 9: 00157-2023 2. NHS England respiratory pathway tool — breathlessness prevalence estimates

CLEAR sample practice dataset — 233,240 patient records, 17 practices across four PCNs, January 2015 to December 2023 | OHID public health profiles | BMA workforce data | NHS England referral to treatment waiting times data | NHS Digital SNOMED CT browser

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