

# Patient experience of COPD care: outcomes from the British Lung Foundation Patient Passport

Keir Philip ,<sup>1</sup> Stephen Gaduzo,<sup>2</sup> Judith Rogers,<sup>3</sup> Michael Laffan,<sup>3</sup> Nicholas S Hopkinson <sup>1</sup>

**To cite:** Philip K, Gaduzo S, Rogers J, *et al*. Patient experience of COPD care: outcomes from the British Lung Foundation Patient Passport. *BMJ Open Res* 2019;**6**:e000478. doi:10.1136/bmjresp-2019-000478

► Additional material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/bmjresp-2019-000478>).

Received 6 September 2019  
Revised 16 September 2019  
Accepted 16 September 2019

## ABSTRACT

**Introduction** The British Lung Foundation (BLF) COPD Patient Passport ([www.blf.org.uk/passport](http://www.blf.org.uk/passport)) was developed as a resource to help people with chronic obstructive pulmonary disease (COPD) and clinicians to consider the care received and identify essential omissions. We used the online data collected to evaluate the delivery of COPD care in the UK from a patient perspective.

**Methods** The patient passport consists of 13 questions relating to key aspects of COPD care including: spirometry confirmation of diagnosis, understanding their diagnosis, support and a written management plan, vaccinations, smoking cessation, physical activity, exercise, eating well, pulmonary rehabilitation, exacerbations, medications and yearly reviews. Data were presented as proportions with an answer corresponding to good care, and plotted over time to identify trends.

**Results** After removing identifiable duplicates, data from 41 769 entries, completed online between November 2014 and April 2019, remained (table 1). Twenty-four per cent reported getting support to manage their care and a written action plan; 53% could spot the signs of an acute exacerbation; 34% had discussed pulmonary rehabilitation and 41% stated they understood their COPD, and their doctor or nurse had explained where to find information, advice and emotional support. A quarter reported not receiving influenza vaccination and a third of those who smoke were not offered support to quit smoking. Even the strongest areas including spirometry-confirmed diagnosis, and knowing the importance of being active and eating well, achieved only around 80%. Response patterns remained stable or worsened over time.

**Discussion** Responses to the BLF COPD Patient Passport identify substantial gaps in patients' experience of care, which did not appear to improve during the 5 years covered. These data provide a unique yet commonly overlooked perspective on care quality, and highlight that new approaches will be needed to meet the ambitions to improve respiratory care set out in the NHS Long Term Plan.

## INTRODUCTION

Recent National Institute for Health and Care Excellence (NICE) guidance for chronic

## Key messages

### What is the key question?

- From a patient perspective, are patients receiving the key aspects of good quality care in chronic obstructive pulmonary disease (COPD)?

### What is the bottom line?

- Substantial gaps exist in patients' experience of COPD care, which do not appear to have improved over the last 5 years.

### Why read on?

- These data provide a unique yet commonly overlooked perspective on care quality—the patients' perspective.
- These data highlight that new approaches will be needed to meet the ambitions to improve respiratory care set out in the NHS Long Term Plan.

obstructive pulmonary disease (COPD) has emphasised the importance of patient information and self-management.<sup>1 2</sup> Although audits<sup>3 4</sup> can assess process and the *delivery* of this and other aspects of care, they are less able to show if aspects have been effectively *received*. A proper assessment of the quality of health services must include patients' perspectives regarding their care. Patient-reported experience measures<sup>5</sup> and patient-reported outcome measures<sup>6 7</sup> are being developed to capture this, although particularly the former are not yet widely used.

The British Lung Foundation (BLF) COPD Patient Passport is an online tool consisting of 13 questions regarded as core components of COPD care (table 1). It was developed with people with COPD, clinicians in the Northwest England Respiratory Team and the Primary Care Respiratory Society (UK). The intention was to raise awareness among patients on what they should expect from respiratory services and help involve them in their care.



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<sup>1</sup>National Heart and Lung Institute, Imperial College London, London, UK

<sup>2</sup>Primary Care Respiratory Society UK, Knowle, UK

<sup>3</sup>British Lung Foundation, London, UK

**Correspondence to**  
Dr Keir Philip;  
[keir.philip@nhs.net](mailto:keir.philip@nhs.net)

**Table 1** British Lung Foundation COPD Patient Passport responses

	Yes (%)	No (%)	Not sure (%)	No answer (%)
Q1: My diagnosis of COPD was confirmed with a breathing test called spirometry.	81.0% (n=33 845)	8.2% (n=3442)	10.3% (n=4302)	0.4%
Q2: I understand my COPD. My doctor or nurse has explained where to find information, advice and emotional support	41.2% (n=17 211)	37.5% (n=12 664)	20.5% (n=8575)	0.8% (n=319)
Q3: I get support to manage my care, and have agreed a written plan with my doctor or nurse about how I will manage my COPD.	24.1% (n=10 048)	61.4% (n=25 650)	13.8% (n=5750)	0.8% (321)
Q4: I contact my GP, nurse or pharmacist to get a free influenza vaccination each year. I have also had the one-off pneumonia jab.	75.7% (n=32 628)	19.2% (n=8005)	4.3% (n=1802)	0.8% (n=334)
Q5: If I smoke, I am offered support and treatment to stop every time I meet my doctor or nurse about my COPD (n=14 395 after removal of non-smokers).	67.2% (n=10 043)	21.4% (n=3200)	9.3% (n=1387)	2.1% (n=310)
Q6: I know the importance of keeping active and eating well.	82.5% (n=34 438)	6.4% (n=2671)	10.3% (n=4315)	0.8% (n=345)
Q7: I have discussed pulmonary rehabilitation.	33.6% (n=14 012)	56.8% (n=23 742)	8.8% (n=3693)	0.8% (n=322)
Q8: I have received advice about ongoing exercise and nutrition.	37.9% (n=15 831)	52.7% (n=22 024)	8.4% (n=3514)	1.0% (n=400)
Q9: I know what all my medicines and inhalers are for and when to take them. I ask my doctor, nurse or pharmacist if I am not sure.	78.8% (n=32 915)	10.4% (n=4338)	9.8% (n=4098)	1.0% (n=418)
Q10: My healthcare professional reviews how I use my inhaler at least once a year. I ask my pharmacist if I have questions.	58.8% (n=24 572)	30.8% (n=12 883)	9.4% (n=3913)	1.0% (n=401)
Q11: I can spot the signs of a flare-up. This is sometimes called an exacerbation and can be the start of a chest infection.	53.0% (n=22 137)	24.3% (n=10 147)	21.8% (n=9112)	0.9 (n=373)
Q12: If I have a flare-up, I know who to contact at any time and what medicines to take. I have these medicines at home.	48.1% (n=20 064)	35.3% (n=14 742)	15.6% (n=6513)	1.1% (n=450)
Q13: I see my nurse or doctor at least once a year to review my health, my care and my treatment, and have time to discuss all the points mentioned previously.	69.5% (n=29 046)	18.0% (n=7496)	11.3% (n=4734)	1.2% (n=493)
Composite total score (mean percentage positive response)	57.9%			

COPD, chronic obstructive pulmonary disease.

The passport can be completed online [www.blf.org.uk/passport](http://www.blf.org.uk/passport) and provides a record of patient experience, relative to a defined standard of care for all people with COPD, similar to a care bundle.<sup>8 9</sup> People with COPD are directed towards this resource by respiratory nurses and doctors during clinical consultations or via targeted online advertising.

Data from online completion provide a resource to analyse the quality of COPD care and potentially to identify trends.

## METHODS

We analysed data from BLF Patient Passport completed between November 2014 and April 2019. The passport is advertised on the BLF website and Facebook.

### Patient and public involvement

Patients were involved in the development of the BLF Patient Passport. In particular, small changes in the wording of questions at the end of 2016 (see online supplementary table 1 in the online supplementary

material for details), resulted from feedback from patients with COPD to improve clarity and encourage people completing the passport to seek out missing care items that had not been delivered. Patients and public were not involved in the current analysis or presentation of these data in this manuscript. However, the central purpose of this manuscript is to highlight the patient perspective as important when considering quality of care.

### Data analysis

Data are presented using descriptive statistics. Responses were excluded from the analysis if no answers, or only one answer, was given and for non-UK addresses. Duplicates identified (same answers, postcode and date of completion) were also removed. For the entire sample, and for each question, total percentage of positive responses (indicating appropriate care) was calculated. Data were also grouped into 6 month blocks, and presented in

bar charts, to explore possible trends. All analyses were carried out using Stata V.14 (StataCorp).

## RESULTS

The initial sample included 44 123 entries. After deletion of duplicate responses as described above, 41 769 remained and were analysed. Results are presented in [table 1](#). Only 24% reported receiving support to manage their care and a written action plan; only 53% could spot the signs of an acute exacerbation; only 34% had discussed pulmonary rehabilitation (PR). A quarter reported not receiving influenza vaccination and a third of COPD smokers were not offered support to quit smoking. Even the strongest areas, including a spirometry-confirmed diagnosis, vaccination and knowing the importance of being active and eating well, achieved only around 80%.

Patterns of response were generally stable over the 54 months of data collection (see graphs 1–13 in the online supplementary file), or tended to decline, with the exception of inhaler technique review, which demonstrates a step up in 2016 from around half to two-thirds of patients responding positively, although this may represent an artefact due to a change in the text asking about review ‘every time seen’ to ‘at annual review’ (supplementary table 1).

## DISCUSSION

This large online sample of UK patients with COPD reveals significant gaps in the delivery of important aspects of patient care and patient understanding of COPD and thus their ability to self-manage. Worryingly, there was no apparent improvement over time, suggesting a need for systemic change.

### Significance of findings

The significance of these findings relates both to the impact of omissions in care and to the need for efforts to understand why the system is failing to deliver them and what needs to change in order to improve matters. Self-management, particularly including an exacerbation action plan, improves quality of life and reduces hospital admissions in COPD.<sup>1</sup> The persistently low positive response rate to self-management items, including having a written plan and being able to recognise and act on symptoms of acute exacerbations is concerning as this may translate into preventable and distressing acute hospital admissions.

Pulmonary rehabilitation is one of the highest value COPD interventions.<sup>10</sup> Referral rates to and delivery of PR remain inadequate, both according to national audit data<sup>3 4</sup> and in the present patient survey. Since PR is a highly effective venue for delivering educational and other multidisciplinary components of COPD care, addressing this would likely be mutually reinforcing. The gaps in care here may also help explain the findings

from the BLF Breath Test, that among breathless people (Medical Research Council (MRC) dyspnoea score  $\geq 3$ ), 58% of those who had sought medical advice reported that this had not helped with their breathlessness.<sup>11</sup> A system failure to provide optimal COPD care also contributes to poor access to more specialised treatments such as lung volume reduction procedures.<sup>12 13</sup>

Particularly weak areas include understanding of COPD and where to find information; having support to manage COPD and a written plan regarding COPD management; discussion of PR; receiving advice about ongoing exercise and nutrition; identifying and managing exacerbations and having yearly review of their disease and management, with time to ask questions. The NICE guidance<sup>2</sup> emphasises the need for comprehensive written information about COPD, including in self-management plans (eg, BLF materials at [blf.org.uk/COPD](http://blf.org.uk/COPD)).

Some areas are slightly better, but still arguably inadequate, including immunisations; smoking cessation (when relevant) and the importance of eating well and staying active. The best areas relate to knowledge of medications and having a COPD diagnosis based on spirometry. These topics have only around 80% responding positively to these questions.

Our findings mirror data from the National Asthma and Chronic Obstructive Pulmonary Disease Audit Programme,<sup>4</sup> from the quality outcomes framework<sup>3</sup> and from the clinical practice research database<sup>14</sup> indicating that key high-value items of care<sup>10</sup> are not being delivered systematically to all patients with COPD, particularly smoking cessation, influenza vaccination and PR. Similar results in audit datasets support the validity of the BLF Patient Passport. In particular, Quality Outcomes Framework (QOF) data report 88% of people with a diagnosis of COPD having had spirometric confirmation of the diagnosis, compared with 81% in the present data.<sup>4</sup> QOF data on influenza vaccination are also similar. According to QOF, 88.7% were reviewed by a health professional in the last 12 months, compared with 70% reported this in our data.

Why has COPD care not improved? The period covered here coincides with the UK Government’s choice to pursue austerity economic policies. These have been shown to impact on health in two ways.<sup>15</sup> The first is via a reduction in support to address or mitigate the social and corporate determinants of health which worsens health and increases the burden on the healthcare system. The burden of austerity falls more heavily on poorer people and COPD is more common in people in lower income deciles. The second mechanism is a direct healthcare effect where resources to deliver healthcare are limited, in particular ‘time to care’. Particularly concerning is the downward trends observed in the responses to questions which represent the more time intensive aspects of care provision. Although it is possible to improve aspects of COPD care with appropriate targeting and prioritisation,<sup>16–18</sup> COPD and respiratory disease in general have not been



afforded the same degree of priority as other aspects of health such as cardiovascular disease. We speculate that the absence of prioritisation and targets could mean that clinicians' finite attention has inevitably been focused elsewhere.

The inclusion of respiratory disease, finally, as a priority in the NHS England Long Term Plan may mark a turning point, helping to translate the burden of need in respiratory disease into effective policy.<sup>19</sup> The NHS RightCare Pathways 'aim to provide a set of resources to support systems to concentrate their improvement efforts on where there is greatest opportunity to address variation and improve population health'.<sup>20</sup> These are focused on (i) pulmonary rehabilitation: optimising patient uptake and service provision, (ii) medicines optimisation for inhaler use: staff training programmes for patient inhaler use and (iii) COPD: case finding, accurate and earlier diagnosis.

### Methodological issues

This study has some potential limitations. Demographics and disease severity were not collected. However, as the main method of signposting to this resource is by respiratory specialist nurses, respiratory physicians and respiratory support groups such as BLF BreatheEasy, the results likely represent the breadth of demographics and disease severity seen across the NHS. It is unlikely that many people without a formal diagnosis of COPD completed the questions, both because of the way that the survey was signposted and because there is no obvious motivation for large numbers of people without COPD to do so.

Some degree of selection bias is possible as completion requires computer access and literacy. As not all respondents gave their postcode, some duplicate records may remain. Similarly, it is possible that some people completed the questions on more than one occasion. However, given that the tendency to complete the questions multiple times is unlikely to be systematically linked to positive or negative responses, the impact of such limitations are not felt to excessively compromise conclusions.

Clearly, one system driver for better care would be increasing requests by informed patients to receive items of care that they are currently missing out on. Although providing information about patient experience, these data do not allow us to address the effectiveness of the COPD Patient Passport in its proposed role as a tool to inform and motivate patients to overcome barriers to receiving better care.<sup>21</sup>

### CONCLUSION

UK patients' responses to the BLF COPD Patient Passport identify substantial gaps in healthcare delivery. Little evidence exists of improvement over the 5 years reviewed, and these findings should prompt new approaches if the NHS Long Term Plan ambitions to improve respiratory care<sup>19</sup> are to be met.

**Contributors** The authors meet criteria for authorship as recommended by the International Committee of Medical Journal Editors. All the authors played a role in the content and writing of the manuscript. In addition, KP performed the analysis of the data, NSH and KP prepared the first draft, SG helped to develop the original questions for the BLF Patient Passport.

**Funding** KP was supported by National Institute for Health Research Academic Clinical Fellowship award and the Imperial College Clinician Investigator Scholarship. The funders had no say in the design and conduct of the study; collection, management, analysis and interpretation of the data; preparation, review or approval of the manuscript and decision to submit the manuscript for publication.

**Disclaimer** This publication presents independent research. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** The present analysis of anonymised data was approved by the British Lung Foundation information governance process. External ethical approval was not deemed necessary.

**Provenance and peer review** Not commissioned; internally peer reviewed.

**Data availability statement** No data are available. Data are held by the British Lung Foundation.

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### ORCID iDs

Keir Philip <http://orcid.org/0000-0001-9614-3580>

Nicholas S Hopkinson <http://orcid.org/0000-0003-3235-0454>

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